Wisconsin History of Advocacy and Mental Health Services

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Introduction

In order to commemorate the 25th anniversary of the passage of the Americans with Disabilities Act, the Wisconsin ADA Partnership/ADA Legacy Project was established in 2014. A subgroup focused on only mental health services was created to document the history of Wisconsin's mental health service system. This group consisted of representatives of state and county government, advocates, consumers, family members, and service providers.

The group decided to identify issues and trends that predated the passage of the ADA. Wisconsin has been a leader in the development of mental health services since the mid-1970's when its unique state/county partnership for the delivery of mental health services was created. It also was an early leader in the family and consumer advocacy movements. It has long recognized the rights of persons receiving mental health services, including treatment in the least restrictive environment, and more recently the importance of recovery and trauma informed services.

The mental health subgroup has produced the following papers, which are part of this document:

Themes that Weave Through the History of Wisconsin Mental Health Services
Historical Highlights of Wisconsin Mental Health Service System
NAMI Wisconsin History
Mental Health Consumer Movement in Wisconsin
History of the Development of the Child Mental Health Advocacy Movement in Wisconsin
History of Infant Mental Health Services
Madison Model
Challenges that Remain

Themes that Weave Through the History of Wisconsin Mental Health Services

Focus on Community Based Services

In the early 1970's a group of staff at Mendota Mental Health Institute developed an experimental program to treat persons with serious mental illnesses in the community. This program became known as the Program of Assertive Community Treatment (PACT). Research showed it to be highly successful in enabling persons to live successfully in the community and avoiding hospitalizations. Funding was eventually secured to spread PACT type programs, which were known as Community Support Programs (CSP), across the state. Wisconsin was the first state to pass legislation mandating CSPs in every county and to develop CSP as a Medicaid benefit.

Treatment providers and parents of children with serious emotional and behavioral disturbances also wanted a community treatment option and thus pushed for the development of the Integrated Services Program (ISP), also known as Children Come First. This is a wrap-around program involving all the service systems in a child's life as well as the family. Milwaukee Wraparound, a Medicaid managed care program for children's mental health services, has become a national model. While development has been slower than desired, children's mental health programs are spreading throughout the state.

As consumer voices gained strength, a more flexible consumer focused service option was desired. Thus, Comprehensive Community Services (CCS), a Medicaid funded service, was developed and is being implemented statewide.

Additional initiatives to develop crisis intervention programs, supported employment, and independent housing have also been important components of the mix of community based services.

State/County Partnership

Wisconsin's mental health service delivery system was substantially revised in 1974 with the creation of county mental health boards, which had responsibility for the full array of mental health services. Funding from state hospitals was transferred from the state to the counties, giving counties greater flexibility in use of the funds while also making them responsible for paying for state hospital care. A state block grant was created, called Community Aids, which provided additional flexible funding for county delivered services. The state provided oversight to the county based system while also developing new service initiatives such as CSPs and the ISPs.

In many parts of the state this partnership worked well, with counties such as Dane County, developing an array of effective community services. In other areas older models with more focus on institutional care remained. This has created difficulties in work force development and distribution. However, CSPs now exist in all counties and CCS is expanding.

The State enhanced access to Medicaid for many community mental health services, such as CSP and CCS, but did so by providing only the federal share, requiring the counties to use the existing Community Aids distribution along with local tax levy to provide the matching funds. While this made sense at the time, the State's failure to increase Community Aids over time to match inflation and the increase in demand for services meant that counties needed to increasingly rely on local tax levy to

maintain or expand services. As counties differed in their capacity or willingness to do so, this led to disparities in access to community mental health services across the state. Thus, while an important model, the state/county partnership has not had uniform success.

Strong Consumer and Family Advocacy

The Alliance for the Mentally III, now known as the National Alliance on Mental Illness (NAMI), was born in Wisconsin. In 1977 three mothers of sons with serious mental illness banded together to form an organization that advocates for respect and support for family members as well as more effective mental health services. In 1979 at a conference in Madison the NAMI was established. NAMI-Wisconsin has chapters throughout the state and has been a leader in family support and education as well as advocacy for better mental health services.

Families of children with serious emotional disabilities came together in 1987 to establish Wisconsin Family Ties (WFT). This organization developed a program of family advocates to help individual families get better services. In addition they have been an effective voice in securing better treatment for children with serious emotional disabilities statewide.

In the 1980's mental health consumers were starting to organize. In 1988 the first consumer organization, Wisconsin Network of Mental Health Consumers, was formed and the first consumer conference was held. Over time, over 26 local consumer projects have been developed, a strong statewide organization, the Grassroots Empowerment Project (GEP), has emerged, a peer specialist initiative has been implemented, and peer run respite programs created.

Collaboration between Advocates and Policymakers

While not always in agreement, Wisconsin has been marked by a high degree of collaboration between various advocacy groups and state and county mental health policymakers. For example: Disability Rights Wisconsin (the state's protection and advocacy organization), NAMI-Wisconsin, and the state Department of Health and Social Services (now Department of Health Services) worked closely to develop legislation and funding for CSPs. These organizations plus GEP collaborated on the development of CCS. WFT has been a strong ally of the state and counties in developing ISPs for children. Mental Health America (MHA) worked closely with other advocates and the Department on mental health parity legislation.

The various individuals and organizations have been brought together by mutual respect and a desire to improve the lives of persons with serious mental illnesses or emotional disabilities. They have also worked together through the Wisconsin Council on Mental Health, Wisconsin's federally required mental health planning and advisory council. Policymakers have listened to the voices of advocates and have framed various initiatives around what they have heard. Advocates have been willing to participate since they feel valued and respected.

Strong Legal Protections

In 1972 Wisconsin's civil commitment law was declared to be unconstitutional. As a result the law was substantially rewritten to provide protections against involuntary treatment. In addition, a strong patient rights section was created which grants the right to treatment in the least restrictive environment, a right to prompt and adequate treatment, and many other rights regardless of where the person is receiving services – hospital, community, public or private services. Overtime, enforcement

mechanisms such as administrative regulations, a statewide grievance procedure, and the ability to go to court have been added.

Some of the protections in the civil commitment law have been changed over time, such as the addition of a non-dangerous "fifth standard" for commitment. Nonetheless protection of consumer rights remains a priority.

Mental Health and Criminal Justice System Involvement

Persons with mental illness become involved with the criminal justice system in several ways. First individuals found incompetent to stand trial or not guilty due to mental disease or defect (the "insanity defense") are committed to the State for treatment. However, the State's commitment to community treatment has had an impact here. Persons may be evaluated for competency while in the community. Persons committed under the "insanity defense" may receive treatment in an institution or under a conditional release in the community. The state funded and administered "conditional release" program has been exemplary in reducing recidivism and rehospitalization.

Unfortunately, many individuals with mental illness have been caught up in the mainstream criminal justice system. As the prison system expanded in the 1980's and community mental health treatment resources declined in the 1990's many more persons with mental illness ended up in prison or jail. However, treatment resources in criminal justice facilities did not expand resulting in many persons with mental illness serving time in solitary confinement and not receiving the medications and other treatment they need. Recently, an initiative has been launched to provide aftercare services for persons identified as mentally ill based on the "conditional release" model with the goal of reducing recidivism and successful reintegration back into the community. Additionally, Wisconsin has been increasing funding to allow counties to develop more "problem-solving courts" which allow individuals to be diverted from jails to supervised community based treatment.

Finally, when, in 1994, Wisconsin passed a civil commitment law for sexually violent persons who have already served their prison sentences, resources for community mental health services were diverted to fund institutional treatment for this population. Commitments initially exceeded expectations resulting in the opening of a 300 bed facility in 2001 which was expanded to 500 beds in 2009. In 2012 the annual operating budget was over \$50 million.

Services Based on Values

While there has long been a value placed on services which are respectful, humane, and in the least restrictive environment, in 1997 the state adopted Recovery as the guiding vision for its mental health system. This has led to a shift in beliefs about what consumers can achieve in life, the development of hope, a change in relationships between consumers and treatment providers, and the development of services based on consumer goals and preferences.

More recently, there has been a recognition of the impact that trauma has had on the lives of many persons with mental illness. This has led to an initiative to implement trauma informed care throughout services for both adults and children. Services should be based on the values of trust, safety, empowerment, choice and autonomy. The goal is to promote healing as well as recovery.

Stigma and Discrimination

Stigma and discrimination against persons with mental illness has long been an issue. Positive statewide efforts to address the issue were made in 2002 when Healthiest Wisconsin 2010 listed mental health disorders as one of the state's top 11 public health priorities and Wisconsin United for Mental Health was initiated. This public/private partnership has undertaken education and training initiatives throughout the state to address the issue. More recently WISE – the Wisconsin Initiative on Stigma Elimination – has been developing training to support people in their decision about whether, when and how to disclose their mental health issues.

Historical Highlights of Wisconsin Mental Health Services System Updated: November 2014

- 1857 State legislature authorizes an act to establish a mental illness facility (or State Hospital for the Insane) for treatment of acute patients. Mendota State Hospital (or State Hospital for the Insane) is built.
- 1873 Northern State Hospital for the Insane is built in Oshkosh (Winnebago). Beds are rapidly filled.
- **1880** Milwaukee County Asylum is opened to receive chronic and acute patients from Milwaukee County.
- **1881** Statutory authority is passed by Legislature to allow counties to establish county asylums for the admission of chronic patients.
- **1900** Thirty-two county facilities are operational with about 5,000 beds.
- 1909 On February 19, 1909, Beers, along with philosopher William James and psychiatrist Adolf Meyer, embraced that future by creating the National Committee for Mental Hygiene, later the National Mental Health Association and what we know today as the Mental Health America.

 1915 Central State Hospital for the Criminally Insane is built. Southern Wisconsin Colony for the Mentally Retarded is built.
- 1926 First Child Guidance Clinic opens in Milwaukee as a result of the mental hygiene movement. Several clinics open around the state. Later, maternal and child health (Title IV) funds are used to partially fund the clinics.
- 1930 At the federal level, Division of Mental Hygiene is created in the Public Health Service.
- 1936 Insulin shock treatment is introduced at Mendota State Hospital.
- 1944 Minimum standards for county asylums are developed and passed.
- 1946 At federal level, the Hill-Burton Hospital Construction Act is passed. National Mental Health Act is passed, it authorizes the establishment of the National Institute of Mental Health (NIMH).
- 1947 Wisconsin Mental Health Act, Chapter 51 is passed. The Director of the Department of Public Welfare is designated as the state mental health authority. Division of Mental Hygiene is established at the Department.
- 1951 The names or county asylums are changed to county hospitals.
- 1955 The revolution of antipsychotic medications begins with Thorazine.
- 1955 The inpatient population reaches its highest level. There are 1,150 patients at Winnebago, 950 at Mendota and about 12,000 at county hospitals. State hospital staff begin to consult with county hospitals on patient care.
- 1963 The Mental Health Centers Act is signed into law by President Kennedy. Several

Community Mental Health Centers are funded in Wisconsin.

- 1969 Training in Community Living (TCL) Program is established through Mendota State Hospital, to do research and provide intensive community services to persons with chronic mental illnesses. This community treatment program later became known as Program of Assertive Community Treatment (PACT).
- 1971 Chapter 51, the State Mental Health Law is amended. Under 51.42 it creates community program boards and places the responsibility for the planning, provision, and funding of mental health services for residents on the county and the fiscal responsibility for state hospital care on counties. County hospitals are changed to county nursing homes to take advantage of available Medicaid funds. State Hospitals became State Mental Health Institutes with new duties and responsibilities.
- 1972 Lessard decision declares WI commitment law is unconstitutional.

PACT moved from Mendota Mental Health Institute to a community location in downtown Madison.

1974 Based on the Lessard vs. Schmidt the state changes the involuntary commitment process in every county.

The state allocates funds and the county community program boards become responsible for planning of the use of these funds in the areas of mental health, developmental disabilities, alcohol and other drug abuse, effective January 1, 1974.

Chapter 51 is amended to include patient rights.

- Ch. 55 Protective Services Law is created and Ch. 880 Guardianship Law is substantially revised
- **1976** PACT efficacy is demonstrated thru research by Len Stein and Mary-Ann Test.
- **1977** Dane County Alliance for Mentally III (AMI) is established by three mothers of persons with severe mental illness.
- **1978** Community Support Program (CSP) capacity building funds are allocated to provide community based services to people with chronic mental illnesses.
- At NIMH, the Community Support Program Branch is established.
- Ch. 51 "Trailer Bill" focus on patient rights, confidentiality, children's inpatient admission, some modifications to commitment standards and procedures.
- **1977-79** A Legislative Council Study Committee on the care of chronically mentally ill persons makes recommendations for service improvement.
- 1979 Dane County AMI invites organizations representing persons with severe mental illness to a

meeting in Madison. As the result of this meeting, The National Alliance for the Mentally Ill is established.

Central Wisconsin Hospital in Waupun is closed after a new forensic unit is opened at Mendota.

Dane and Kenosha counties receive funds to develop case management services for children with severe emotional disturbance.

1981 Creation of NAMI Wisconsin

1983 Chapter 51 is amended to mandate that all counties provide CSP services.

At the federal level the Reagan Administration enacts a policy to cut off people with mental illness and severe emotional disturbance from Supplemental Security Insurance (SSI). Advocacy organizations file a lawsuit and the benefits are restored in Region V.

Jones decision – creates right to refuse psychotropic medication.

1984 CSP funding has grown from the original \$800,000 to \$5.1 Million.

HSS 92 – confidentiality regulations created

1985 Act 139 – some minor changes to commitment standards and procedures.

Act 176 – county human services restructuring with more control county executives to appoint mental health and human service directors and boards.

1985 Act 176 – county human services restructuring; more control to county executives to appoint MH/HSD directors and boards. Watts vs. CCSB establishes right to annual review of protective placements in court.

1986 -1987 Legislative Council Special Committee on Mental Health Issues

1987

Act 366 – right to refuse medications; medication as protective service; settlement agreements; focus on access to CSP; discharge from homeless shelters; death reporting requirements; minor modifications to commitment standards/procedures

1988 HSS 94 – patient rights regulations created.

Wisconsin Family Ties is established with federal grant funds.

1989 Medicaid funds are no longer available to pay for services for individuals between ages 22-64 in nursing homes determined to be Institutes for Mental Disease (IMD). The State Legislature allocates funds to pay for nursing home care for these institutions. Eight nursing homes are determined to be IMDs and receive the special allocation.

Medicaid Targeted Case Management becomes available for all persons with disabilities including persons with mental illness.

Wisconsin prepares the Mental Health Plan in response to Public Law 99-660.

The Federal Fair Housing Amendments Act is passed. It includes prohibition of discrimination of persons with psychiatric disabilities in housing.

The first WI consumer Conference is held in Madison.

1990 CSP program standards (HFS 63) are promulgated.

The Office of Mental Health receives funding for Dane County from the Robert Wood Johnson Foundation to develop community services to children with emotional disturbance.

Chapter 46 is amended to include language to encourage counties to develop Integrated Service Programs (ISPs) for children with severe emotional disturbance (46.56).

Revisions to Insanity Defense legislation

1990 Medicaid funds become available for certified CSPs through the Rehabilitation Option.

Five additional counties receive ISP funding.

Americans with Disabilities Act becomes law on July 26.. The Act prohibits discrimination of individuals with disabilities including persons with psychiatric disabilities.

1992 Joint Legislative Audit Committee publishes an evaluation report on oversight of county mental health programs by the Department of Health and Social Services.

Wisconsin's share of the Community Mental Health Block Grant is increased from \$350,000 to \$4 million. The additional funds are targeted to priority community mental health services for children and adults and to consumer and family self-help and peer support programs.

Legislative Council's Special Committee on Oversight of Community Mental Health Services is established. Most provisions of the Americans with Disabilities Act affecting public services and places of public accommodation become effective on January 26.

1993 Wisconsin Act 445 on Mental Health Oversight is passed. The Act makes changes in client rights, mental health program certification, and composition of community/human service boards.

Pre-Admission Screening and Annual Resident Review (PASARR) standards are clarified for admission of persons with mental illness to nursing homes.

Eighteen consumer and family self-help and peer support programs are funded with mental health block grant.

Five additional counties receive funds to establish ISPs.

Children Come First managed care entity is established in Dane County to fund services to children with severe emotional disturbance.

Rolo case establishes the right of conditional release under Chapter 51 for persons found guilty by reason of mental illness and residing in stat mental health institute forensic units.

1994 The Legislature enacts Chapter 980 which creates the procedure for involuntary civil commitment of certain individuals who are found to be sexually violent persons.

Joan S. vs Gudeman settlement leads to Milwaukee County MH master plan.

Milwaukee begins the implementation of adult mental health master plan that includes aggressive downsizing of county's IMD beds and transfer of funds to community service expansion.

The Bureau of Community Mental Health receives a five year \$15 million federal grant to develop wraparound services in Milwaukee. Six more counties receive ISP funding.

1995 Three additional boards serving five counties receive ISP funds.

Sheboygan IMD begins bed downsizing. Only six nursing homes remain as IMDs as the result of relocation and re-evaluation of IMD status.

Milwaukee WrapAround program is established with federal funds.

Legislation is passed limiting county responsibility to fund services.

First statewide Crisis Intervention Conference is held.

ML Settlement leads to reduction of seclusion and restraints at state mental health institutes.

1996 "5th Standard" for involuntary commitment passes; it includes revisions to standards to refuse medication.

The Governor establishes the Blue Ribbon Commission Mental Health. •

Children's day treatment and mental health crisis intervention standards are promulgated to enable programs to capture Medicaid funding.

Congress passes insurance reform that includes elimination of pre-existing conditions in health insurance policies.

Mental health "parity bill" is introduced in Congress.

HSS 94 revised; extensive requirements for grievance procedure created

1997 The 1997-97 biennial budget expands enrollment of AFDC and HealthyStart recipients to Health Maintenance Organizations (HMOs) from five counties to statewide by 1997. Identification

and treatment of mental health needs of the AFDC recipients and their children is now the responsibility of the 51 Boards.

Blue Ribbon Commission on Mental Health Final Report is published. The report embraces the concept of recovery as the guiding vision for Wisconsin's mental health system.

Milwaukee County Mental Health Division creates a Consumer Affairs Office. Dottie Northtrup is the first director.

Winnebago Mental Health Institute hires Larry Schomer to run peer support groups at the Institute.

1998 Bureau of Community Mental Health hires Kellianne O'Brien as the first Consumer Relations Coordinator with a person who has lived experiences.

A statewide consumer organization is created called the Grassroots Empowerment Project, through an RFP using MHBG funds. The project is located at WI Council on Independent Living centers.

Wisconsin received a federal grant to develop innovative program around women and violence. This was a joint effort between the University of WI and the Department of Health and Family Services and continued until 2001.

DHFS establishes the Recovery Task Force to implement recovery concepts state wide.

1999 Mental Health: A Report of the Surgeon General is published.

White House Conference on Mental Health is convened in Washington DC.

Crossroads Conference – first statewide conference related to the effects and the treatment for any type of trauma on an individual's mental health is held in Milwaukee.

2000 The Grassroots Empowerment Project (GEP) is formed as an independent state wide non-profit organization with a consumer board of directors. Molly Cisco is the first Executive Director.

GEP starts convening annual Consumer Empowerment Days in Madison.

2001 Half time Trauma Informed Care Coordinator hired by the BCMH.

The Recovery Task Force publishes a manual titled "Recovery and Mental Health Consumer Movement in Wisconsin".

Wisconsin Alliance for Infant Mental Health is established. Therese Ahlers is hired as the first Executive Director.

2002 Coordinated Service Team Core values published. First CST grants awarded. First CST pilot counties are funded.

Healthiest Wisconsin 2010 lists mental health and substance abuse disorders as two of the top Wisconsin 11 public health priorities.

Wisconsin United for Mental Health (WUMH) established. WUMH is a public/private partnership of several agencies to eradicate stigma through education and information.

Bioterrorism grant submitted by DHFS to the Centers for Disease Control and Prevention is funded to address MH/SA needs in disaster response and recovery.

2003 The President's New Freedom Commission on Mental Health Report is published.

Bureau of Community Mental Health and Bureau of Substance Abuse Services are merged to create the Bureau of Mental Health and Substance Abuse Services.

Division of Disability and Elder Services is created. This brings together community mental health services and mental health institutions into the same organization.

Dennis H case upholds constitutionality of Fifth Standard

2004 Comprehensive Community Services Standard is promulgated.

Milwaukee Mental Health Task Force is established with purpose of identifying issues faced by all people affected by mental illness, facilitating improvements, giving a voice to consumers and families, reducing stigma and implementing recovery principles.

Over 26 consumer self-help/peer support groups operate in Wisconsin.

2005 Act 444 - Children's admission to inpatient is revised

Ch. 55 is rewritten; and Ch. 56 Guardianship law is created

2006 Lt Governor's Task Force on Women and Depression is formed

2007 Division of Mental Health and Substance Abuse Services (DMHSAS) is created.

2008 Federal Mental Health Parity Act is passed called Wellstone-Domenici Mental Health Parity and Addiction Equity Act.

Peer Specialist Committee is formed by the DMHSAS Recovery Task Force. This work group developed the Peer Specialist Code of Conduct, Core Training Competencies, and the Peer Specialist job description, certification application and Guidelines and the WI Peer Specialist Certification Exam.

The First Burden of Suicide in Wisconsin report is published with data from 2001-2006.

2009 First Peer Specialist Coordinator hired by Access to Independence through funding by DMHSAS

MH/AODA Infrastructure Study is completed by TMG with specific recommendations regarding future funding for MH and AODA programs.

The Becky Young Act is passed. Funds become available to promote successful transition of people with MI form prisons to community.

Act 218 - WI mental health parity bill is passed, this fills in part the coverage gap left by Wellstone Domenici Act.

- 2010 First MH Peer Specialist exam was held in various locations around the state.
- **2011** First Communities in Action to prevent Suicide conference is held.
- 2013 Office of Children's Mental Health is created and responsible to the Governor's Office.
- **2014** The Affordable Care Act becomes effective and includes parity in health care coverage for mental health and substance abuse services.

Revisions to emergency detention are approved.

2013 Wisconsin Act 127 signed by the Governor and about \$26 M of additional GPR funds are added to the state budget for mental services.

Milwaukee County continues downsizing of its inpatient units and successfully to close the Hilltop ICF-MR.

The Department of Health Services funds three consumer operated peer respite programs. The grants are awarded to GEP, NAMI Fox River Valley and SOAR in Madison.



Prepared for the 25th Anniversary Celebration of the Americans with Disabilities Act (ADA) by Nancy Abraham with documents on early WI AMI history by Harriet Shetler

January 2016

AMI Wisconsin to NAMI Wisconsin

Among the more significant social movements of the last twenty-some years of the 20th century, as well as the early years of the 21st century in Wisconsin and the United States has been the AMI/NAMI movement. With the establishment of AMI National in 1979 in Madison, WI, families, consumers (patients/clients), providers and friends brought a focus to bear on the brain disorders of the serious and persistent mental illnesses.

The movement, first called the Alliance for the Mentally III (AMI), but in 2005 was modified, as a result of consumers' advocacy, to the Alliance on Mental Illness, has had an impact through advocacy, education and support. However, events at the national, state and local levels have at times brought benefits as well as challenges, and continue to do so. For example, parity in insurance is now the law. But more persons with mental illness are incarcerated due to a variety of factors including, in this writer's observation, most significantly the lack of sufficient numbers of evidence-based and best-practice community-based treatment programs for persons with the brain disorders of serious and persistent mental illnesses.

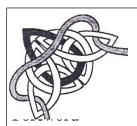
The foregoing pages include:

AMI of Wisconsin Enters Adolescence prepared by Harriet Shetler for inclusion in the 15th Annual AMI of Wisconsin State Conference Program booklet, pages 10-13, now pages 18-23 in this grouping. The conference was held in Appleton, WI, May 17-19, 1996.

NAMI Wisconsin Experiences Growth and Change prepared by Nancy Abraham in preparation for the 25th Anniversary of the ADA (Americans with Disabilities Act) in 2015. Items included were gleaned from <u>The Iris</u> newsletters through the years 1995-2013.

NAMI has made a difference, continues to make a difference, and will in the future continue the very important work of advocating for persons with mental illness, supporting individuals and families, and educating about the brain disorders of serious and persistent mental illness. NAMI <u>is</u> the <u>voice</u> on mental illness.

Nancy Abraham Founding President



AMI of Wisconsin Enters Adolescence

AMI of Wisconsin completed 15 years on April 25, 1996. To attempt to select highlights in this eventful history is a job for a Solomon, not for a mere participant in the decade and a half. We tried to list the spring and fall mee ings, the names of presidents, and developments here and there that became the "footers" of this history-making and second-to-be-organized NAMI state organization (after California).

The biggest omission is a detailed account of all of the legislative advocacy, one of the three goals that all NAMI groups – local, state, and national – set as the motto on a shining hill along with support and education. The heroic efforts of all f ve presidents and many unnamed foot soldiers have helped Wisconsin become the best family-and-consumer-friendly state in the country.

May the next 15 years be as productive!

Harr et Shetler



- During the weekend of April 25-26, 1981, in Madison, AMI of Dane County and UW-Extension co sponsored the organizing meeting of AMI of Wisconsin (AMI-WI
- Held at the Wisconsin Center, the meeting was modeled on the organizing conference of National AMI in September, 1979 (also held in Madison)
- Five affiliates participated: Dane, Fox Valley, Milwaukee, Outagamie, and Racine
- Before the weekend ended, Rock and Fond du Lac joined
- Nancy Abraham was elected chair of a steering committee which was responsible for incorporating AMI-WI (September 24) and organizing the first meeting of the corporation in the fall in Fond du Lac
- AMI-WI elected its first board, with Nancy Abraham of Dane County as President; Bob Nugent of Racine as Vice President; Esther Howard of Milwaukee as Secretary; and Irving Koren of Fond du Lac as Treasurer
- AMI-WI participated with other disability groups in the Rally for a Sane Budget at the Capitol; Nancy Abraham was a speaker, and a busload of Racine AMI members attended
- By December, there were 13 affiliates and a constitution and bylaws were approved

1982

- Three state AMI members Everett Matz, Pam Starr, and Maria Meyer were appointed to the state Mental Health Advisory Council
- Beverly Young was elected state president
- The spring conference was held April 24th in Port Edwards, and the annual meeting was held Sept. 24 25 in Milwaukee
- Esther Howard put out several issues of a state newsletter
- AMI-WI ended the year with 17 affiliates

1983

- AMI-WI's significant advocacy for SSI and SSDI protection was the first of dozens of successful political efforts over the 15 years
- State AMI members took an active role in alerting the public about cancellation of benefits to over 2,000 Wisconsin persons with mental illness
- Harriet Shetler was elected to the NAMI Board as Bev Young completed her four-year term
- State conferences were held in Wausau (April 30th) and Janesville (Sept. 24th)
- This year ended with 25 affiliates and a first letter addressed to "Lions for Mentally Ill"

- The Mark Smith Memorial (Madison) opened the NAMI escrow account for research, later known as NARSAD
- Robert Nugent, winner of the H.F. Johnson Community Service Award, donated the \$5,000 prize to AMI
- At the La Crosse conference (April 28-29) George Myers and Hal Stein proposed formation of a family trust
- Annual meeting took place in Racine

- Pam Erickson (Milwaukee) worked with NAMI to start a national and state network called Help Exists for Loved Ones in Prison (HELP)
- Dr. E. Fuller Torrey spoke at the spring conference in Appleton attended by 400
- NAMI Executive Director, Laurie Flynn, was featured at the fall conference in Madison
- After securing a Child Advocacy (CAASP) project grant, AMI-WI opened its first office at 1245 E. Washington Avenue in Madison
- Linda Scharnberger was hired as project director and Linda Stuart as secretary

1986

- Pat Bohon (Racine) succeeded Bev Young as president of AMI-WI
- Thirty offices in the legislature were represented at AMI's informational forum in the Capitol
- State AMI conferences were held in Eau Claire (spring) and Milwaukee (fall, with Dr. Bert Pepper, speaker)
- AM I-WI state newsletter received first place award from NAMI

<u>1987</u>

- AMI and ARC established the Wisconsin Family Community Trust for the Disabled to help families with estate planning
- AMI-WI sponsored Depression Information Day at the Capitol on April 22
- Four AMI members (Kim Aiello, Mitzi Shogren, Harriet Shetler and Bev Young) were selected for the newly-created state Mental Health Protection and Advocacy Committee, which hired Dianne Greenley as managing attorney and joined the Wisconsin Coalition for Advocacy
- Thirty-two Wisconsin members attending the NAMI annual meeting in Washington and saw La Crosse AMI receive first-place newsletter award for affiliates under 100 members

1988

- Robert Nugent was elected president at the annual meeting November 19th in Madison
- The spring conference in May at Fond du Lac had as speaker Dr. Ned Kalin, research director, at UW Medical School
- At the tenth annual NAMI conference in Boulder, AMI of Racine took first place in newsletter judging of affiliates under 100

<u>1989</u>

- Northwestern AMI affiliates sponsored the May 5-7 conference in Cable with Dr. Werner Mendel, famous psychiatrist-author, as guest speaker and workshop leader
- More than 150 AMI-WI members, consumers, and professional staff marked Mental Illness Awareness Week with a Capitol rally
- Affiliates throughout the state observed the week with rallies, marches, grocery-store bag messages, local radio spots
- The fall annual meeting was hosted by Dane County, recipient of the NAMI Outstanding Affiliate Award (Carol Grogan, President, accepted it at the Cincinnati convention)

- June Wild (Pewaukee) became the third AMI-WI member elected to the NAMI Board at the annual meeting July 19-22 in Chicago
- Although the conference was the eleventh annual meeting, program organizers celebrated a tenth anniversary, recognizing the part AMI-WI had played in the 1979 organizing meeting in Madison
- AMI of Waukesha planned the spring conference around Mary Moller, nurse and educator
- Bob Nugent was re-elected president at the fall meeting in Madison

<u>1991</u>

- The largest state conference ever 675 marked the tenth anniversary of .AMI-WI held in Appleton; Brown County, Neenah/Menasha, Waupaca, Oshkosh, Waushara, and Outagamie were hosts; speakers were Dr. E. Fuller Torrey and NAMI President Tom Posey
- Alidor Vanderport was elected state president at the annual meeting in Madison
- The state office was moved from the basement to the second floor of the Marquip Building
- Combined Health Appeal of Wisconsin accepted AMI as a member

1992

- A Leadership Conference for mental health consumers and family members was held in Green Bay, co sponsored by AMI-WI, WINMHEC (the state consumer organization) and Wisconsin Family Ties (the state organization for families with young children)
- Talk show host Dr. Harvey Ruben was keynote speaker at the spring conference in Madison
- Jennifer Ondrejka joined AMI-WI as Executive Director; a graduate of UW with degrees in
 philosophy and rehabilitation psychology, her responsibilities included fund raising, public
 relations, affiliate development and office administration; Jennifer became editor of the
 newsletter, whose editors had included Esther Howard, Harriet Shetler, Roselyn Calek, Karen
 Paillasse, and Carol Grogan
- At the annual meeting in Madison, Dr. William Knoedler, director of PACT, outlined actions AMI members could take to increase the "priority and visibility of mental illness in Wisconsin"

<u>1993</u>

- Alidor "Har" Vanderport was elected chair of AMI's District 6, State Presidents' Advisory Council
- Donna Murdoch edited and wrote the 1st edition of "Mental Illness, A Family Resource Guide" available for all affiliates
- Dr. Robert Beilman wrote "The Family Perspective on Mental Health Issues" for the Wisconsin Counties Association newsletter
- The AMI-WI newsletter was redesigned and rechristened as The Iris
- AMI WI initiated the AMI Iris Project, a nationwide project using silk irises to increase public awareness of mental illness issues and to raise funds for local affiliates
- NAMI provided a \$5,000 Grass Seed Grant to support the "Mental Illness and the Jail System" workshop series co-chaired by Helen Geyso and Bob Beilman
- Marie Balter, famous consumer and movie heroine, was keynote speaker at the spring

- conference in Milwaukee
- AMI-WI became one of ten states to pilot the Journey of Hope family education and support program; under co-chairs Nancy Abraham and Jennifer Ondrejka, seven two-person teams of teachers and eight support group facilitators became part of the Journey of Hope
- Senator Russell Feingold spoke at the annual fall meeting in Madison
- Pat Bohon was elected president of AMI-WI

<u>1994</u>

- Catherine Beilman and Har Vanderport coordinated state efforts for the NAMI National Health Reform Network
- NAMI president Warren Adams and Mona Wasow, AMI member and UW professor of social work, spoke at the May 6-7 AMI-WI spring conference in La Crosse
- The state office was moved to 1410 Northport Drive in Madison
- A second and expanded edition of the "AMI 'of Wisconsin Family Resource Guide" edited by Jennifer Ondrejka and Donna Murdoch, went into a 12,000 print run
- On the toll-free line, the state organization had handled over 4,000 calls in a year
- Five AMI-WI members went to the first annual Journey of Hope "Train the Trainers" session in Nashville in March; Nancy Abraham, Program Coordinator; Gail Auerbach and Trudy Ciszek, Teacher Trainers; Lorraine Wilcox and Cathy Steffke were Support Group Facilitator Trainers

<u>1995</u>

- Frederick Frese, Ohio psychologist and consumer, later elected to the NAMI Board, and LaVerda Allen, NAMI board member, were featured speakers at the May 12-13 spring conference in Racine
- Journey of Hope classes and support groups reported 17 counties in the network
- State staff included: Jennifer Ondrejka, Executive Director; Linda Stuart, Administrative Assistant; Eileen Cyncor, Director of Development; Kelly Krenke, Secretary; Clyda Nelezen, Bookkeeper; and Kurt Monson, Office Assistant
- AMI-WI ended the year with 28 affiliates and over 1,600 members

NAMI Wisconsin Experiences Growth and Change

Foreword

AMI of Wisconsin, now NAMI Wisconsin, was 33 years in April 2014 with a total of eleven different persons serving as Presidents, and at some points Co-Presidents, from 1996-2014. Change in the Executive Director (E.D.) position occurred in 1996, followed by the hiring of an individual who served in that capacity for over ten years. That, in turn, resulted in the position being served by several individuals including two interim persons. In 2011, the current Executive Director came on board.

The late 1990s in to 2014 were very active, and included among others:

- purchased a "home site" in Madison
- trained volunteer trainers and teachers for NAMI signature programs
- offered NAMI courses in the Madison office and through affiliates
- advocated for Mental Health/Mental Illness Insurance Parity in coalition with other groups
- increased consumer involvement
- sponsored NAMI walks with some affiliates
- concerned involvement for persons with Mental Illness who were/are incarcerated

The brief synopsis, by year, from the latter part of 1995 to 2014 involves information gleaned from the NAMI Wisconsin newsletters, <u>The Iris</u>. While the following pages do not contain the myriad of activities, decisions, actions, and untold hours of both staff and volunteers (both in the office and in the state), it provides a brief timeline overview.

The needs and the work needed continues.

Nancy Abraham Founding President

- Pat Bohon, President; Mel Story, Secretary; Mike Mallon, Treasurer; and Bob Nugent, outgoing Vice President
- Bohon says "one of the key responsibilities of the AMI movement to communicate a vision of an effective community mental health system... with the needs of the individual consumers"
- Catherine Beilman with others works on Mental Illness insurance parity
- Journey of Hope Training (now FTF) occur in Eau Claire and Milwaukee
- Fifth Standard to Civil Commitment
- Susan Mader recaps 1995 Wisconsin Consumer conference, which was held in Madison

1996

- Executive Director Jennifer Ondrejka leaves in summer as National NAMI Regional Director for Campaign to End Discrimination against People with Brain Disorders
- Robert Beilman, President; Gene Duncan, Vice President; Mel Story, Secretary; Mike Mallon, Treasurer
- Staff includes Donna Wrenn, Executive Director; Linda Stuart, Admin. Assistant for over 10 years; Diana Steffen, Development. Director; Carin Mizera, Project Director (Grassroots Empowerment Project); Kelly Esser, Secretary; Kurt Monson, Office Assistant
- National NAMI Executive. Director Laurie Flynn comes to Madison in August to help dedicate Tellurian's Teresa McGovern Center
- Managed care, insurance parity concerns
- PACT and Managed Care Conference in Ft. Worth, Texas attended by Deborah Allness, Dylan Abraham, Nancy Abraham, David De Lap; Stephanie Karwacki, Linda Keyes, William Knoedler, Tim Otis, Pat Rutkowski and Mary Ann Test
- NAMI-WI takes stance re: Managed Care
- "Touched with Fire", art exhibits in three locations on UW-Madison campus; over 10,000 view; over 250 attended reception and lecture by Susan Spaniol on artistic creativity and mental illness.
- Robert Beilman NAMI-WI representative to State Blue Ribbon Commission.
- Fall conference in Madison.
- Wausau State Consumer Conference
- Fall Leadership in Madison
- 500 people benefit from Journey-of-Hope education/support
- Family & Consumer Resource Guide reaches 25,000 plus
- AMI Iris Project initiated by AMIWI used by 200 plus affiliates
- Fifth Standard to civil commitment passed

- 31 Affiliates in Wisconsin
- Robert Beilman, President; Richard Ganzer, Vice President; June Wild, Secretary; AI Vandenberg, Treasurer
- Donna Wrenn, Executive Director; Carin Mizera, Project Director; Dale Johnson, Affiliate Development Specialist; Amy Diehl, Administrative Assistant; Kurt Monson, Office Assistant
- NAMI family education of JOH (Journey of Hope) becomes Family-to-Family (F-T-F)

- Generous amounts from the Mosher family of Appleton and Don Levy of Madison, the latter for the Bridges project
- Wisconsin Family Community Trust for the Disabled includes AMI Members Harold Stein, attorney, and Mel Story, previous AMI Secretary
- AMI working with Voc. Rehab. and Bureau of Community Mental Health to include vocational specialist in each CSP in Wisconsin
- Fall Conference in Madison, "Crossing Bridges to Independence; Jana Frey, PACT Director, speaks on role of employment in the recovery process
- John Quaal, AMI Legislative co-chair attended 2nd National Consumer, Family and Advocate Leadership on State Health Care Reform and Managed Care in Maryland
- More discussion of Managed Care in Wisconsin
- Need continues for state insurance parity law

- 29/31 Affiliates
- Richard Ganzer, President; Mitch Vesaas, Vice President; Eileen Mader, Secretary; Al Vandenberg, Treasurer
- Donna Wrenn, Executive Director; Dale Johnson, Affiliate Development Specialist; Darlene Hammon, Financial Director; Marie Chevalier, Administrative Assistant; Kurt Monson, Office Assistant
- NAMI National decides National Alliance on Mental Illness, rather than National Alliance for the Mentally Ill as the official title of the organization, but NAMI is retained as the acronym
- Gene Duncan and John Quaal appointed to Blue Ribbon Commission Follow-on committee
- Work on 4th edition of NAMI-WI Family and Consumer Resource Guide
- Speaker's Directory
- Catherine Beilman, Harriet Shetler and Bev Young worked on publication of 1998 NAMI-WI Legislative Advocacy Handbook
- Focus on insurance parity, managed care, better vocational services and fund-raising
- Wisconsin mandates two (2) days of specific education for all Division of Vocational Rehabilitation (DVR) counselors to learn about mental illness and strategies
- Objections to use of term <u>behavioral health</u> as we move into an era of managed health care; see it as a return to a former era that viewed mental illness as "bad behavior"
- Spring conference in Waukesha in May; Consumer Conference in Green Bay
- Ask the Doctor begins in newsletter
- Direct caregiver of family member with mental illness has right to information under Wisconsin Statutes § 51.30 (4) 20 of the Mental Health Act to diagnosis/prognosis; medications; and individual treatment plan... professional needs to let consumer know.

<u> 1999</u>

- 32/31 Affiliates
- Officers Richard Ganzer, President; Mitch Vesaas, Vice President; Eileen Mader, Secretary; Robert Beilman, Treasurer; Donna Wrenn, Executive Director; Marie Chevalier, Administrative Assistant; Vicky Rami, Administrative Assistant; Kurt Monson, Office Assistant; Elaine Carpenter, Volunteer

- August 26,1999, papers signed for office building at 4233 W. Beltline Rd., in Madison: down
 payment possible through endowment from Lucille Orbison, long-time NAMI member; move
 in completion by end of October; need some renovations
- Need to continue fund-raising for 4th edition of the Guide, as well as Spanish language version. 50,000 copies distributed via first three (3) editions
- Twelve teaching teams, with 17 people trained in August 1998; Claire Ryan joined Trainer Team along with Gail Louise Auerbach and Don Levy
- NAMI-WI joined coalition to fight for fairness in health insurance
- Efforts continue to divert persons with mental illness from jails into treatment
- NAMI Para Los Hispanos por Irma Gosselin appears in Spanish in Vol. 18, No. 1 issue of <u>The</u> Iris
- June conference in Madison
- Work Group re: Young Families involves NAMI-WI, Family Ties and Bureau of Mental Health
- Susan Heidrich, PhD, RN and NAMI-Dane, public participant in evaluating NIMH Research Grants.

- 31 Affiliates
- Frank Ryan, President; Richard Ganzer, Past President; Mitch Vesaas, Vice President; Eileen Mader, Secretary; Robert Beilman, Treasurer
- Staff included Donna Wrenn, Executive Director; Marie Chevalier and Vicky Rami; Administrative Assistants; Kurt Monson, Office Assistant; and Elaine Carpenter, Volunteer
- The new building Capital Campaign led by former Governors Lee Dreyfus and Tony Earl as Honorary chairs, Co-chairs Bev Young and Harriet Shetler, with Frank Ryan, Mitch Vesaas, Richard Ganzer, along with Pat Bohon and Art Koch
- The new site will provide a Training and Education Center, as well as a permanent home for a growing resource library (to facilitate loaning resources)
- Jan Greenberg received a research grant from NIMH for the first large study to help families plan for the future
- Diane Gooding, NAMI-WI Board member and Asst. Prof. of Psychiatry and Psychology at UW-Madison, research study of those with schizophrenia regarding emotion, perception and brain functioning
- Impact of cuts in Federal Block Grants and community aids
- Parity, waiting lists, jails and persons with mental illness issues of concern
- I Vote, I Count; PACT being replicated throughout the United States
- Mental Illness is the World Health Organization's number one priority in 2006
- Fumiko Mclain, NAMI-Wishigan (NAMI-WI board member) spoke in Zenkaren National Congress 2000 (Japanese) NAMI Convention in Shuzoka, Japan in November
- 350 at conference in Green Bay
- Frank Ryan helped to bring NAMI-WI story to major news media
- Provider Education (10 week course) and Vision for Tomorrow Trainings occurred
- Use of Seclusion and Restraints in Wisconsin article by Diane Greenley in The Iris.

- 31/33 Affiliates
- Frank Ryan, President; Richard Ganzer, Past President; Mitch Vesaas, Vice President; Eileen Mader, Secretary; Robert Beilman, Treasurer
- Donna Wrenn, Executive. Director; Marie Chevalier, Administrative Assistant; Victoria Rami, Director's assistant; Kurt Monson and Rosie Quinn, Office Assistants; Elaine Carpenter, Volunteer
- 20th Anniversary of NAMI-WI, April 21-22 Conference "Education Our Call Empowerment Our Challenge" at Four Points Sheraton in Milwaukee
- Anniversary dinner April 20th. Speakers for the 20th included Dr. Ron Diamond and Julian Swartz, who left the UW-Madison basketball team because of mental illness
- Fall one day leadership conference regarding Legislative Advocacy
- NAMI-WI building Capital Campaign goal of \$300,000 with \$130,000 initial goal; American Institute of Architects Southwest Chapter donated architectural services per Kent Calloway
- Mental Health Courts discussed by both E. Michael McCann (Milwaukee) and Brian Blanchard (Dane) to their local NAMIs saying circuit court judges in each county "hold the key"
- First stage NAMI-WI website launched; 4th edition Resource Guide published on-line, as was the Children's Resource Guide
- Provider Education course in September- 5 persons team(s)
- Visions for Tomorrow Training in July 2 person team(s)
- Education Trainings (see <u>The Iris</u> Vol. 20, No.3, pg. 2); leadership Training for Helping Caregivers Develop Plans for the Future in August-Agnes Hatfield to speak
- Joint Training in Milwaukee with Very Special Arts (VSA) and Milwaukee Public Schools on March 23 by NAMI-WI, WI Family Ties and VSA WI; the information shared could reach up to 6,000 with 1,000 being students with disabilities
- Two NAMI WI members honored by Transitional living Services, Inc. (TLS Board Annual meeting in Milwaukee); Maria Von Schrader, NAMI-Racine and Dylan Abraham, NAMI-Dane).

- 32/33 Affiliates
- Frank Ryan, President; Robert Beilman, Past President and Treasurer; Mitch Vesaas, Vice President; Eileen Mader, Secretary
- Donna Wrenn, Executive Director; Marie Chevalier and Skye Lavin, Administrative Assistants; Francesco Mesa, Development Director; Kurt Monson, Office Assistant; Elaine carpenter, Volunteer; Bob Fox, Construction Volunteer
- Capital Campaign at \$225,000. Kent Calloway, AIA and employee of Flad help pro bono; help on the building labor costs donated by Bricklayers and Allied Craft Workers, as well as MATC Mason's Apprentice Program
- Robert Beilman and Frank Ryan involved in fund raising
- Conference in April in Racine
- NAMI-WI scheduled 9 trainings Family-to-Family (offered for 6 years,800 gone through course), 1st Provider Education, 1st Peer-to-Peer, Elder Peer Support, Elder Caregiver Education Teacher Training, Advocacy Training and Inclusion Forum (diversity)

- Parity in insurance in Wisconsin Capital Times, Wisconsin State Journal, and Milwaukee Journal/Sentinel in support of parity
- Conference on Mental Health and Substance Abuse Issues in Criminal Justice co-sponsored by NAMI-WI January 16-17, at the Country Inn Hotel, Waukesha

- 33 Affiliates
- Frank Ryan, President; Robert Beilman, Past President and Treasurer; Mitch Vesaas, Vice President; Jim Pelzer, Secretary
- Donna Wrenn, Executive Director; Skye Lavin, Administrative Assistant; Francesco Mesa, Development Coordinator; Kurt Monson and Dennis Wilder, Office Assistants; Elaine Carpenter and Robert Fox, Volunteers
- NAMI-WI building renovation almost completed; fund-raising tiles installed in entry and foyer
- NAMI-WI/CSP conference in lake Geneva in April, included Consumer Arts & Crafts Fair; 109 presenters, with 650 attendees (the largest)
- NAMI-WI and NAMI-Waukesha selected to be state site for NAMI Walks for the Mind of America (May 5, 2004) to be held in 40 communities in the nation; purpose Mental illness/health awareness and fundraising
- NAMI-WI awarded two contracts, one from WI Dept. Health and Family Services Mental Health Recovery Implementation Grant (2 Staff) and for WisPACT, WI Pooled and Community Trust to complete some administrative work (1Staff)
- WisPACT II established, Supplemental Needs Trusts
- Corrections Meeting with Matt Frank, Department of Corrections Secretary and NAMI-WI members Helen Geyso, Robert Beilman, John Quaal and Frank Ryan; issues included conditional release program at Wisconsin Residential Centers; mental illness screening tools for the jails and prisons; and after-care release
- President's New Freedom Commission Report on Mental Health- need to transform Mental Health System in U.S.

- 33/32 Affiliates
- Frank Ryan, President; Robert Beilman, Past President and Treasurer; Mitch Vesaas, Vice President; Jim Pelzer, Secretary
- Donna Wrenn, Executive Director; Jennie Loewenberg, Training Specialist; Kellianne O'Brien; Kurt Monson and Dennis Wilder, Office Assistants; Elaine Carpenter and Robert Fox; Volunteers; Kristin Nelson-Hubbard, Laura Ragsdale and Melissa Marsh
- Annual Conference in Appleton in May
- Third Annual Midlife and Aging Families: Planning for the Future Workshop- Joan Liegel, Barbara Lindsay, and Barbara Wolff organized; Jan Greenberg, supervised Evaluation Report
- Advocacy Training Day
- Affiliate leadership Day
- First Crisis Intervention Training (CIT) in Wisconsin at NAMI-Fox Valley
- Mind of America inaugural walk in Wisconsin in Waukesha May 15th
- NAMI-WI Recovery Project progressing
- NAMI-WI Consumer Council formed in October 2004

- First year of State Recovery Contract wrapped up by NAMI-WI; delivered practitioner competence training to 250 home health workers in Shawano and Menominee Counties
- WisPACT, Inc. operating for one (1) year, they will hire own staff
- Ongoing issues Medicaid and medications prior authorization, vulnerability of Section 8
 Housing vouchers, difficulty to obtain dental care on Medicaid; lack of insurance parity;
 managed care; and privatization of care in jails
- Dane County Sheriff Gary Hamblin agrees to join NAMI-WI Board
- Helen Geyso cites Wisconsin Statutes § 302.38 (1), "Sheriff has the duty to provide appropriate medical care or treatment to an inmate. Negligence in fulfilling this duty is a tort."

<u>2005</u>

- 32 Affiliates
- Nancy Phythion, Co-President with Frank Ryan (term ended April); Robert Beilman, Past President and Treasurer; Carol Mixdorf, Secretary; Nancy Phythion, President; Frank Ryan, Past President; Brad Munger, Vice President; Carol Mixdorf, Secretary; Gary Hamblin, Treasurer
- Donna Wrenn, Executive Director; Jennie Loewenberg, Kellianne O'Brien, Kurt Monson and Dennis Wilder, Elaine Carpenter, Robert Fox, Kristen Nelson Hubbard, Laura Ragland, Melissa Marsh
- Annual Conference in Waukesha in April; Andrew Sperling with National NAMI spoke on impact of Medicare Part D (medications) in effect January 2006 covers SSDI/Medicare and dual-eligibles who receive SSI & SSDI who are currently covered by Medicaid
- Second Annual NAMI walk at conference April 29
- Trainings- IOOV (2X), Hand-to-Hand program for parents and families of children and adolescents
- Building Blocks for Affiliates with NAMI Regional Coordinator, Steve Buck in April
- La Crosse and Outagamie affiliates pursuing Mental Health Courts
- Ask the Doctor column with Leslie Greenspan continues in The Iris, along with Ken Hermann, Ken's Kids Corner article
- NAMI-WI library continues to grow
- NAMI-WI representatives met with Wisconsin Dental Association regarding dental care and Medicaid; number of college students growing, are underserved
- Name change of NAMI from "for the mentally ill" to "on mental illness;" acronym remains NAMI.

- 32/33 Affiliates
- Nancy Phythion, President; Frank Ryan, Past President; Ken Hermann, Vice President; Carol Mixdorf, Secretary; Gary Hamblin, Treasurer
- Staff and volunteers in office Donna Wrenn, Executive Director (October 26th, 10 years in role), Jennie Loewenberg, Kellianne O'Brien, Kurt Monson and Dennis Wilder, Elaine Carpenter, Robert Fox, Laura Ragland, Melissa Marsh, Vaunceil Kruse

- Annual Conference in April at the Marriott in Middleton, 25th anniversary NAMI-WI
- Lifetime achievement awards to Dr. Wiiliam Knoedler (Chief Psychiatrist, PACT), and Dr. Harry Knaz
- President Phythion requests affiliates share e-mail data base with NAMI-WI related to need for improved communication per feedback from affiliates
- Board develops strategic plan
- Jim Maddox and JoAnn Stephens, co-chair NAMI-WI Consumer Council
- Mid-life... in April in Madison
- Consumers and Providers Working Together Workshop in Wausau in May
- Mel Haggart, MD in Ask the Doctor column of <u>The Iris</u>
- UW-Madison Affiliate first listed in October 2006 Affiliates roster
- Issues included, Taycheedah, as well as other state prisons not meeting need of those with mental illness; ACLU sues regarding Taycheedah; after 12 years, still no parity (41other states have)
- NAMI National expanding its Faith/Net
- NAMI's Grading the States rates Wisconsin with a B- (Vol. 22, No. 21 The Iris)

- 33/31 Affiliates
- Frank Mixdorf, President; Ken Hermann, Vice President; Carol Mixdorf, Secretary; Gary Hamblin, Treasurer
- Office staff and volunteers Jennie Loewenberg, Interim Director; Vaunceil Kruse; Melissa Marsh; Kurt Monson and Dennis Wilder; Robert Fox
- Annual Conference May 4-6 in Wisconsin Rapids, cohosted by WI Family Ties, with NAMI Portage/Wood Counties and NAMI-Mid-Central
- NAMI-WI Consumer Council Survey which issues affect you or your family and which are important
- NAMI-WI receives NAMI National Membership Grant
- First non-event fundraiser, NAMI-WI Packer Tailgate non-event
- "Healing Arts" at NAMI-WI; members of Consumer Council host the evening first in what became annual event; (not first arts show- "Touched with Fire" in 1996, a one-time experience on UW-Madison campus)
- NAMI-WI presents Canvas filming on May 5th at MATC Truax campus; a family's journey through mental illness; Patty Loew and Nancy Abraham spoke also
- Parity battle ongoing; legal settlement regarding Paxil for children; Trauma Summit by Department Health and Family Services in May

- 32/34 Affiliates
- Early part of year Frank Mixdorf, President; Ken Hermann, Vice President; Carol Mixdorf, Secretary followed by Pat Rutkowski and Geoff Greiveldinger, co-presidents; Ken Hermann, Vice President; Sandy Hall, Secretary; Terrence W. Schnapp, Treasurer

- Staff and Office Volunteers Jennie Lowenberg, Interim Director, followed by Terrence Schnapp as Interim Director; Cheryl Porior-Mayhew becomes Executive Director at the end of January; Jennie Loewenberg, Vaunceil Kruse, Kurt Monson and Dennis Wilder, Melissa Marsh, Amy Dombrowski and Robert Fox
- Annual Conference in April with Family Ties in Racine
- Focus on enhancing NAMI WI organizational structure (based with work from outside consultant retained in 2007); Summer 2008, <u>The Iris</u> delineates six (6) committees, regarding By-Laws change
- Consumer Leadership Summit at Green Lake Conference Center in July
- NAMI Consumer Council sponsored Special Registration Deputy Training- 19 qualified to register citizens to vote
- "Healing Arts", 2nd annual reception hosted by Consumer Council
- Over 1,000 family members in state reached through Family-to-Family in 2008
- Susan Mader attends National WRAP Facilitator Training
- Focus on Evidence- based practices, i.e. PACT (ACT)
- NAMI-WI Walks in Milwaukee, Waukesha, Dane, Brown, Fox Valley, nearly 3,000 total walked
- The Nicholas Family Foundation, Milwaukee provided \$32,000 in support of Family and Consumer Resource Guide
- Received WI Department of Health and Family Services Consumer Support & Education Grant to begin in 2009, with possible two one-year renewals
- PARITY PASSED IN WISCONSIN AFTER 12-YEAR SAGA
- Water problems in NAMI-WI building in winter

- 34 Affiliates
- Pat Rutkowski and Geoff Greiveldinger, Co-Presidents; Ken Hermann, Vice President; Sandy Hall, Secretary
- Staff and Office volunteers included: Terry Schnapp, Interim Executive Director; Lannia Syren, Executive Director (beginning in May); Vaunceil Kruse, Jennie Loewenberg, Sara Mroz, Gail Louise Auerbach; Don Pirazzoli; Kurt Monson and Dennis Wilder
- Annual Conference in late May at the Marriott, co-hosted with NAMI-Dane
- NAMI-WI priority goal in 2009 "to ensure that mental health care is an integral part of health care reform"
- Family-to-Family (FTF) Director Gail Louise Auerbach to prepare community outreach manual for NAMI-WI affiliates result of F-T-F conference call with Jennie Loewenberg and Gail Louise Auerbach
- Northeast WI affiliate and NAMI-WI hold Outreach Mini-Conference in November at NAMI-Fox Valley
- NAMI Walks in Brown, Dane, Fox Valley, Greater Milwaukee and Waukesha
- NAMI-WI hosts breakfast September 25 with former Norwegian Prime Minister, Kjell Magne Bondevik at Inn on the Park in Madison; Mr. Bondevik took a leave of absence as Prime Minister because of depression; the event included Stoughton Dancers, which kicked off Mental Illness Awareness Week – NAMI-WI, WI United for Health, Mental Health America of Wisconsin and Lilly USA, LLC.
- NAMI-WI Consumer Council Health and Wellness Fair in November at Marriott in Madison

- Third Annual "Healing Arts" show and reception
- Classes on consumers as Providers and Elders and Mental Illness; First Family-to-Family Teacher Leadership Summit
- U.S. economic downturn taking a toll on American mental illness and health funding
- Wisconsin prisons provide substandard care regarding mental health
- Report on State Prisons regarding Mental Health released
- Chief Justice Initiative on Mental Health and Criminal Justice System
- State to charge counties for services at MMHI and WMHI for Medicaid recipients who are under age 21 and 65 and older; the federal portion of the Medicaid reimbursement will pay about 60% and the counties about 40%.

- 35/32 Affiliates
- Pat Rutkowski and Geoff Greiveldinger, Co-Presidents; Sandy Hall, Vice President; Robert Wrenn, Secretary
- Staff and office volunteers Lannia Syren, Executive Director; Jennie Loewenberg, Vaunceil Kruse; Kate Bahr, Gail Louise Auerbach, Maria Hanson, Bob Fox, Andrea Clark, Kurt Monson and Dennis Wilder
- Annual Conference in Green Bay, co-host NAMI-Brown County April 30 May 1 with 399 in attendance; Consumer Leadership Summit April 29th in Green Bay
- Consumer-led affiliates Mid-Central, Northwoods, Southwest and Washington County
- NAMI-Fox Valley Peer-to-Peer on Native American Tribal Lands; and Greater Milwaukee African American Program (ASK-Access, Support and Knowledge)
- NAMI-Dane Peer-to-Peer class at Mendota Mental Health Institute
- NAMI-Dane & VA Hospital Family-to-Family
- Mental Health Insurance Parity law (2009 Wisconsin Act 218) was signed by Governor Jim Doyle on April 29, 2010
- President Barack Obama signs the Patient Protection and Affordable Health Care Act March 23, 2010
- 2010 Teacher Leadership Summit in Stevens Point in November
- Collaborative 2nd Wisconsin Warrior Project: Madison Summit June 15-16 at MATC-Truax
- UW Madison Affiliate hosts "Healing by Design: Art Therapy as a Tool for Recovery from Mental Illness", organized by Ed Erwin, held in Red Gym at UW-Madison April12-19.
- 4th Annual "Healing Arts" show hosted by Consumer Council at NAMI-WI
- Karen Aspenson, Fox Valley, Executive Director and Sgt. John Wallschlager, Appleton Police Dept. honored with International CIT Advocate of the Year and International CIT officer of the Year at the International CIT Conference in San Antonio in June

- 32/31Affiliates
- Geoff Greiveldinger and Sandy Hall, Co-Presidents; Pattie Jo Severson, Vice President; Robert Wrenn, Treasurer; Terry Ryan, Secretary
- Staff and office volunteers Lannia Syren, Executive Director (until summer); Julianne Carbin, Executive Director (beginning in fall); Jennie Loewenberg; Vaunceil Kruse; Gail Louise Auerbach; Maria Hanson; Andrea Clark; Kurt Monson and Dennis Wilder; Bob Fox and Carol Grogan

- Annual Conference April 15 16 in Milwaukee, co-hosted by Greater Milwaukee and Waukesha
- Consumer Leadership Summit in Milwaukee in April
- "Pieces in My Own Voice", component of ASK presented
- NAMI-WI Strategic Plan process completed
- Planning for the Future in late April at American Family Insurance in Madison
- Parents and Teachers as Allies launches in WI
- Research Grant to support smoking cessation project with NAMI-WI and University Center for Tobacco Research and Intervention awarded 13 CSPs in eight (8) counties agreed to partner-trained peer specialists who were former smokers
- Hispanic Family-to-Family classes over past four (4) years in NAMI Kenosha
- "Healing Arts" show and reception at NAMI-WI hosted by consumers
- Family Education Summit in November with course developer Joyce Burland in attendance
- NAMI-WI team attends Dartmouth College re: promote supported employment throughout state

- 31 Affiliates
- Sandy Hall and PattiJo Severson, Co-Presidents; Dave DeLap, Vice President; Terry Ryan, Secretary; Christine Fountain, Treasurer
- Staff and office volunteers: Julianne Carbin, Executive Director; Jennie Loewenberg, Vaunceil Kruse, Andrea Clark, Maria Hanson, Kurt Monson, Dennis Wilder, Jo Anderson, Bob Fox, Carol Grogan
- Annual Conference May 6-7, in Stevens Point
- Beginning in 2012, no longer separate Recovery Newsletter within The Iris
- Minority mental health awareness a priority for NAMI-WI
- Need for increased mental health services on college campuses
- NAMI-WI and Department of Corrections training CIT (Crisis Intervention Training) to personnel in state correctional facilities; four (4) teams to train supervisory staff beginning in June
- Planning for the Future Workshop in Madison in September "Voices of Experience" conference in Brookfield to 75 providers of services to homeless by consumers
- NAMI Walks in Brown, Dane, Fox Valley, Greater Milwaukee and Waukesha
- Sixth Annual "Healing Arts" show and reception at NAMI-WI in October, hosted by Consumer Council
- Reaffiliation process by NAMI-WI to be complete in 2012; will support the local affiliates through the process

<u>2013</u>

- 31/32 Affiliates
- Jim Connors, President; Dave De lap, Vice President; Kathy Rohr, Secretary; Sandy Hall, Treasurer
- Staff and office volunteers: Julianne Carbin, Executive Director; Gail Louise Auerbach; Andrea Clark; Annabelle Potvin; Neivette Regalado; Colleen Rooney; Sara Yanke; Maria Hanson; Kurt Monson; Dennis Wilder; Chelsea Strangeway; Bob Fox; Carol Grogan and Jo Anderson
- Annual Conference April 26 27 at the Marriott in Madison

- NAMI-WI By-Laws update to be in line with NAMI's National Standards of Excellence
- NAMI-WI recognized by NAMI regarding the Outstanding NAMI State Organization Award
- July Minority Mental Health Awareness Month for Wisconsin
- "Healing Arts" seventh annual at Crescendo Cafe in Madison in October
- Fifth Annual Teacher Leadership Summit recognizing 20 years of Family-to-Family course in Wisconsin in November; annual Claire Ryan Award for Distinguished Service in Family Education received by Pat Woicek; Gail Louise Auerbach recognized for 20 years of service Family-to-Family course added to National Registry of Evidence Based Programs and Practices (LAMHSA).

Mental Health Consumer Movement in Wisconsin

Updated March 2016

1980	Lighthouse, a small consumer group, has space at that State Office on Mental Health in Madison with access to copying, phone, mailings. They also publish a newsletter.				
1984	Larry Schomer, a mental health consumer from Neenah, starts giving presentations about living with mental illness to community groups and university classes. He is invited to give the key note address at the 1984 statewide Wisconsin AMI Conference.				
1985	Larry Schomer is the second consumer to be appointed by the Governor to the Wisconsin Council on Mental Health (the first consumer appointed to the Council was Glen Zwicki but not sure what year). Dylan Abraham, a mental health consumer from Madison, becomes a speaker/trainer to Madison Police recruits about mental illness and how police officers should deal with people with a mental illness whom they encounter. He continues to provide this training for ten years and over a twenty year period gives over 700 presentations to middle school and high school students, university and technical college classes and community groups.				
1988	Elaine Carpenter, supervisor at the Office of Mental Health writes and receives a consumer grant from the CPP Branch of the National Institute of Mental Health. WCA hires two consumers to plan the first consumer conference in January. The Wisconsin Network of Mental Health Consumers (WINMHC) is organized with an office in Madison and regional offices in May. The first Wisconsin Consumer conference is held in June.				
1989	This consumer grant is contracted to Wisconsin Coalition for Advocacy (WCA) now Disability Rights Wisconsin, to administer. Two consumer staff are hired, Betty Blaska and Patrick Irick. A statewide consumer advisory committee is established. The second Wisconsin Consumer Conference is held in October.				

1980's	In the late 1980's the statewide Community Support Program (CSP) conference starts including consumers on conference planning committees, holding consumer roundtables during conferences and encouraging county CPS to bring consumers to attend the conference.			
1990	Grants are made to local consumer groups and to WINMHC.			
1991	WINMHC is abandoned amid accusations of mismanagement. Schizophrenia Bulletin publishes an articvle by Betty Blaska titled: First Person Account: What it is like to be treated like a CMI".			
1992	Federal MH block grant is significantly increased. Consumers speak forcefully at a public hearing in support of devoting funds from the mental health block grant increase for consumer and family self-help and peer support. \$480,000 annually is allocated.			
1993-1994	Rae Untzicker, a national consumer leader consults with Wisconsin consumers in an effort to heal the movement. The consumers recommend that DHFS not fund a statewide consumer agency			
1993-1995	Seventeen consumer and family self-help and peer support programs are funde with the mental health block grant funds.			
1994	Larry Schomer is the first consumer to be elected Chair of the Wisconsin Council on Mental Health.			
1995	Crossroads Conference on Trauma held in Milwaukee. Consumers play a major role in planning the conference ad presenting at the conference. Dylan Abraham is among a handful of consumers hired by the Mental Health Center of Dane County to work as a Peer Support Specialist for the Emergency Services Unit.			

1996	Grassroots Empowerment contract is awarded to NAMI Wisconsin. Carin Mizera is hired to head the program. Eighteen local projects are funded. Kathleen Crowley, a mental health consumer, writes the chapter on Procovery for the Blue Ribbon Commission on Mental Health report articulating recovery principles. Later Kathleen writes and publishes a book on Procovery and establishes the Procovery Institute in California that works on implementing Procovery in several states.				
1997	Winnebago Mental Health Institute hires Larry Schomer to run peer support groups at the Institute. BRC report is published emphasizing recovery, consumer involvement. Milwaukee County Mental Health Division creates a Consumer Affairs Office, first of its kind in Wisconsin. The first director is Dottie Northrup.				
1996-1997	Blue Ribbon Commission (BRC) on Mental Health is convened. Initially, only two consumers are appointed. Consumers approach the Governor's Office and several additional consumers are appointed changing the tone of the committee.				
1998	Consumer Relations Coordinator position is established at the State Bureau of Community Mental Health. Kellianne O'Brien is hired as the first Consumer Affairs Coordinator. When Kellianne leaves Wendy Warren is hired and serves in this position until she dies in 2011. In 2015, Ellie Jarvie holds this position. Recovery Implementation Task Force is established by the bureau of Community Mental Health. The statewide consumer program, called Grassroots Empowerment Project (GEP), is rebid through the RFP process and moves to Wisconsin Coalition of Independent Living Centers.				
1999	Larry Schomer with Barry Blackwell and Joann O'Connor publish a paper titled: Consumer Staff in Psychiatric Inpatient Facilities."				

2001	Grassroots Empowerment Project (GEP) becomes an independent 501(c) 3 not for profit organization with a consumer controlled board of directors. Molly Cisco is hired as the first executive director. The Recovery Task Force publishes a manual titled: "Recovery and Mental Health Consumer Movement in Wisconsin". Statute securing consumer and family self-help and peer support funding is passed as part of the biennial budget.				
2002	GEP starts convening annual Consumer Empowerment Days to bring peers together to establish what issues are important to consumers and then deliver those messages to policy makers.				
2004	Over 26 consumer self-help/peer support agencies exist in Wisconsin.				
2006-2007	Peer specialist Subcommittee of the Recovery Implementation Task Force is established.				
2008	Bureau contracts with Access to Independence to develop peer specialist certification process and a career ladder for peer specialists.				
2009	GEP Convenes the Consumer Leadership Academy with funding from the first SAMHSA Statewide Consumer Network Grant awarded to GEP.				
2010	Peer specialist certification exam is implemented.				
	GEP partners with Optum Health, Options for Independent Living, NAMI Greater Milwaukee, and NAMI Racine to implement PeerLink program to provide peer support to Optum members to decrease emergency room visits and hospitalizations and increase access to community services.				
2013	Biennial Budget provides funds to pilot peer run respite programs in Wisconsin.				
	State funding for consumer self-help and peer support services are rebid through the RFP process and the contract is awarded to the Great River Independent Living Center in LaCrosse.				

2014	State funding for consumer self-help and peer support services are rebid through the RFP process and the contract is awarded to the Great River Independent Living Center in LaCrosse.	
2016	There are 428 peer specialists certified in Wisconsin.	

Development of the Child Mental Health Advocacy Movement in Wisconsin

Maggie Mezera

In the mid-to late 1980s several significant events occurred which launched and supported the child mental health advocacy movement in Wisconsin and in other states around the nation. In 1985 the state was awarded one of ten federal CASSP (Child and Adolescent Service System) grants to begin to develop a system of care for children with serious emotional and behavioral disorders. CASSP required grantees to address the need for family involvement and advocacy. So, from 1985-87 AMI of Wisconsin had a contract with the state to initiate the Child Advocacy Project, which had as its goal of organizing parents into a support, education and advocacy network in the state.

During that time also, the Technical Assistance for Parents Program (TAPP) and the Research and Training Center on Family Support and Children's Mental Health at Portland State University in Oregon began a study of existing organizations of and for parents of children and adolescents with serious emotional disabilities. There was an interest in learning the extent to which these families were separately organized or were included in multidisciplinary disability organizations. In addition, the Portland Center began a series of regional conferences called, "Families as Allies." Several Wisconsin parents who ultimately became members of the steering committee that formed Wisconsin Family Ties attended one of those conferences, held in Indiana. There, concepts of parent-professional partnerships and family advocacy were introduced. The conferences were an important milestone, as parents and professionals met to discuss ways to improve services for families that included children with serious emotional disabilities. A natural outgrowth of that process was the realization that these families needed to organize.

Early in 1987, parents from nine local Wisconsin support groups formed a steering committee. In June, 1987, Wisconsin Family Ties was launched as a statewide independent organization to provide support, education and advocacy to families that included children with serious emotional disabilities. Coincidentally, this occurred within one month of when "Kids in Crisis," an important analysis of the status of children's mental health services in the state, was published.

In the summer of 1988, the National Institutes on Disability and Rehabilitation Research and the National Institutes of Mental Health jointly allocated \$100,000 with the intent of funding existing parent groups to assist them in the development of stable statewide parent organizations. The goals were: (1) to stimulate and support the development of model statewide parent organizations that could provide technical assistance, information and support to parents within the state and (2) to evaluate the implementation and outcomes of these models with the goal of promoting effective approaches. Forty seven organizations applied and five \$20,000 Statewide Demonstration Grants were awarded. Wisconsin Family Ties received one of those grants. The funding was used to open a small office in Madison and hire a part-time employee. The Wisconsin Coalition of Advocacy, next door, served as fiscal sponsor until the not-for-profit status was completed.

Wisconsin Family Ties was, in subsequent years, awarded additional federal Statewide Demonstration Grants and began expanding their funding base. A number of employees, called Family Advocates, all parents themselves, were hired to work out of their homes in various locations in Wisconsin. The administrative staff was headquartered in Madison.

The first of several working conferences entitled "These Too are Wisconsin's Children," was convened in Madison in mid-November, 1988, to identify issues important in the development of a collaborative statewide children's mental health system. Wisconsin Family Ties parents played a significant role in the conferences. It was concluded that that the system should be sufficiently funded, coordinated, comprehensive and strength-based. Families were encouraged to advocate to receive the services and support they needed to keep their children at home and in the community, to be involved as full partners in the design, delivery and evaluation of services and when policymaking decisions were made.

In early 1989, Wisconsin Family Ties sponsored the first of five regional conferences that year that featured speakers who described an innovative legislative proposal developed as a result of the "These Too are Wisconsin's Children" conferences. These were a first Wisconsin Family Ties venture into systems advocacy. Ultimately, those grassroots and collaborative efforts resulted in the passage in late 1989 of s.46.56, "The Integrated Services Program for Children with Severe Disabilities" Act, commonly known as the "Children Come First" Act.

Wisconsin Family Ties continues today to serve families by providing support, education and advocacy services. Its statewide parent advocates are now working as "parent peer specialists." A significant systems advocacy victory was achieved in February, 2013, when \$30 million of new state funding for mental health programs and initiatives was announced. Two initiatives high on WFT's priority list were a statewide expansion of the Coordinated Services Team Wraparound initiative (an outgrowth of the Integrated Services Programs) and the establishment of an Office of Children's Mental Health at the state level to coordinate and integrate mental health services which are provided across multiple state agencies.

Wisconsin Alliance for Infant Mental Health

Therese Ahlers, MS, MPA, IMH-E® (IV)

Background

The Wisconsin Alliance for Infant Mental Health (WI-AMH) began with the efforts of a few individuals whose work centered on infants, young children and their families. These individuals recognized unmet mental health needs in the infants, young children and families they worked with. The concerned professionals started to meet to discuss the viability of a state-wide effort to promote the social and emotional development of infants and young children.

In November of 2000, ten Wisconsin representatives along with representatives from five other states attended a Midwest Summit in Chicago to discuss infant mental health efforts in their respective states. The Wisconsin representatives learned that infant mental health promotion, prevention and intervention strategies were organized efforts throughout the Midwest. Both Michigan and Illinois had Infant Mental Health Associations for several years. The Chicago Summit inspired the Wisconsin participants to create an initiative devoted to early childhood mental health policy and practice. Upon returning to Wisconsin, the group contacted Jim Ryan, the President of Penfield Children's Center, a Birth to 3 agency in Milwaukee, to lead the effort to start a state-wide entity promoting developmentally appropriate policies and practices supporting healthy development starting from birth.

What is Infant Mental Health?

Infant and early childhood mental health is the social and emotional development of the youngest children and is formed within the context of relationships. It is a child's ability to experience, regulate, and express emotions, to form close and secure interpersonal relationships, and to explore the environment and learn (ZERO TO THREE, 2003). It involves skills such as self-confidence, curiosity, motivation, persistence, and self-control which affect growth, trust, and future learning.

The earliest years lay the foundation for future success in school and beyond. Research from the field of infant and early childhood mental health confirms that a child's emotional development is the basis for all later development as it sets the stage for relationships and readiness to learn. Children who do not attain basic social and emotional milestones do not do well in school. These children are at a higher risk for behavioral problems and juvenile delinquency.

The Early Years: A steering committee was formed and a draft vision and mission developed. Jim Ryan was successful in securing first year funding. The Mental Health Association in Milwaukee County (MHA) agreed to serve as the fiscal agent for the newly formed organization. Therese Ahlers was hired as the director in October 2001. The following individuals were members of the original steering committee guiding the development of the organization in the early years:

- Ginnie Cleppe
- Donna Harris
- David Hoffman
- Irv Raffe
- Martha Rasmus
- Raquel Reyes
- Jim Ryan

Vision and Mission: The new organization focused efforts on supporting the social and emotional well-being of children birth – five years of age and their families. The vision of the organization is to aim for all Wisconsin infants and young children to reach their fullest potential through nurturing and consistent relationships with the context of family, community and culture. The mission is to strive to promote infant mental health through building awareness, promoting professional capacity, fostering partnership and supporting policies which are in the best interest of infants, young children and their families.

The strategies used to promote infant mental health include:

- **Increase public awareness** of the influence of early experiences and relationships and impact on development
- **Develop professional capacities** to understand and support infants and young children within their relationships
- Foster partnerships, policies and best practices to better support healthy development in infants, young children and their families

Wisconsin Infant and Early Childhood Mental Health Plan

Efforts in the early years focused on increasing public awareness and developing a plan to support the healthy social and emotional development of young children. In October 2002, WIIMH hosted an Infant and Early Childhood Mental Health Summit. Over 100 participants, representing a variety of disciplines and parents, gathered to share their thoughts on the challenges and opportunities related to infant and early childhood mental health. Participants at the Summit were divided into five mixed discipline work groups and answered questions related to public policy, training, and service delivery. The data gathered was used as a starting point to develop the Wisconsin Infant and Early Childhood Mental Health Plan.

Four sub-committees were created to develop the plan: policy, service delivery, training, and public awareness. The goal of each sub-committee was to develop recommendations using the information gathered at the Summit. The sub-committees met over a nine month period and developed goals, strategies, and implementation tasks related to their sub-committees. Members of the steering committee then compiled the recommendations of each subcommittee. An edit committee compiled the recommendations into one plan and reviewed for completeness and flow. Next, a review team comprised of individuals from rural communities, particularly northern Wisconsin and including parents, provided content suggestions regarding applicability to their specific setting and experience. Finally, a system/expert review team provided edits based upon their respective expertise. A meeting at the end of January, 2004 brought the planning development participants together to determine next steps in moving the plan forward.

Recommendations found in the plan were developed by a variety of people including parents, grandparents, and representatives from a range of private and public entities that work with children. This plan represents the next step to creating an effective system of mental health care for infants and young children. It weaves the best infant mental health practices and principles into the everyday activities of people interacting and working with infants, young children and their families. It also addresses training, communication among service systems, funding and reimbursement, and public policies that support young children and their families.

Current Activities

Since 2001, starting with one full-time staff, the organization has evolved over the years and in 2016 has five full-time staff. Work continues to focus on raising awareness, increasing professional capacity, and supporting public policy that weaves relationship based practices into the day to day activities of all who touch the life of young children. Following are highlights of the last several years summarizing Wisconsin Alliance for Infant Mental Health initiatives, strategies and efforts to support the youngest citizens of our state.

Increasing awareness has been an ongoing practice since WI-AIMH's start. Staff regularly present at state and local conferences sponsored by service areas supporting young children such as child care home visiting, public health, and child welfare. In 2010 WI-AIMH organized its own conference providing two keynote presenters and over 20 workshops over two days. Every even year a two day conference is held in June bringing national experts to Wisconsin to speak on how best to support babies. In odd numbered years, a one day Institute is held offering different content options allowing audience the time to fully explore the details and nuances of infant mental health policies and practices. Since 2003, WI-AIMH has published an electronic newsletter, *Early Relationships Matter*. The format includes a lead story featuring a variety of issues including guidance on best practices to changes within the organization. Also included in every issue are an array of infant mental health stories including current research, links to national publications, funding prospects and upcoming community and state events including and training opportunities. Over 1200 subscribers receive the quarterly newsletter. (http://wiaimh.org/newsletter/)

In 2004 WI-AIMH launched an infant mental health website. The website provides a home for information sharing on infant mental health activities in Wisconsin. WI-AIMH also has a social media presence with a Facebook page that is updated 5 – 6 times per week. Facebook allows WI-AIMH to engage more professionals, family members and organizations across Wisconsin and beyond. Followers include individuals from states across the country and eight other countries.

Developing professional capacity is a cornerstone of WI-AIMH. Given the critical nature of early childhood experiences and the scientific evidence of relationships influencing brain development, all providers touching the life of a young child need to know how to support social and emotional wellbeing. In 2009, WI-AIMH purchased the license for an infant mental health competency and endorsement system from the Michigan Association of Infant Mental Health. *The Endorsement for Culturally Sensitive, Relationship-Focused Practice Promoting Infant Mental Health* was developed over a ten year period by Michigan clinicians, providers and policy makers reflecting a commitment to best practice in the infant and family field. The competencies identify the knowledge, skills and reflective practice needed by all providers across disciplines working with young children and families providing prevention, early intervention and treatment services. As of early 2016, 23 states across the country have adopted the Infant Mental Health Competency and Endorsement system initially developed in Michigan. http://wiaimh.org/endorsement/imh-e-competency-guidelines/)

In 2010, WI-AIMH partnered with the University of Wisconsin in developing the Infant, Early Childhood and Family Mental Health Certificate Program. The Certificate program has evolved and is now a Capstone program of the University whereby students receive graduate credit for successful completion of course work. The University Infant Mental Health curriculum offers two pathways, foundational offering infant mental health theory as well as prevention and early intervention strategies and a clinical tract offering theory, prevention, early intervention and clinical treatment strategies to use with young children and their families. The curriculum is based in part of the competencies adopted from Michigan. (http://infantfamilymentalhealth.psychiatry.wisc.edu/)

Training professionals on practices supporting healthy social and emotional competence is critical. WI-AIMH modified the National Child Traumatic Stress Network curriculum *Caring for Children Who Have Experienced Trauma: A Workshop for Resource Parents* to align with the developmental needs of children birth to age five. The 16 hour curriculum will be delivered to birth parents, resource parents (foster, adoptive and kinship) and early childhood professionals. The adaptations acknowledges the importance of early relationships as well as the importance of parent's self-awareness.

WI-AIMH provided cross-disciplinary training and ongoing support to professionals on the Neurorelational Framework (NRF). The NRF recognizes the negative impact toxic stress can have on brain development and provides practical strategies to buffer the negative impact. Planning has begun to implement a baby court team using the NRF as a framework.

WI-AIMH also helped coordinate Child Parent Psychotherapy training, an evidence based therapeutic treatment for children birth to five with trauma histories. The intervention works to heal the scars of trauma while strengthening the child parent relationship.

Home visiting is an evidence based practice supporting mothers with young children. WI-AIMH is involved in a multiple year project integrating reflective practice and mental health consultation into the home visiting programs across the state. The work helps home visitors and their supervisors build skills to effectively work with infants and builds community capacity to provide mental health consultation.

The Pyramid Model for Social and Emotional Competence is an evidence based prevention and intervention framework promoting social and emotional competence. Developed by the Center on the Social and Emotional Foundations of Early Learning, Pyramid framework supports positive relationships, creates engaging environments, provides concrete teaching strategies and if needed, creates individualized interventions for children. WI-AIMH has had a leadership role in implementing the Pyramid Model throughout Wisconsin since 2009.

Parents Interacting with Infants (PIWI) is a parent group process using the Pyramid Model framework. PIWI groups work to strengthen the parent child relationship and help parents understand the developmental and emotional needs of their babies. The six week group promotes healthy brain development by helping parents engage, connect and understand their babies.

In addition to providing training to select groups of individuals, WI-AIMH also supports community organizing and outreach in support of families with young children. Technical assistance has been provided to communities to develop plans on how providers can work together to support social and emotional well-being of infants, young children and their families. Other community efforts have centered on raising public awareness of the importance of social and emotional development in the first three years of life.

WI-AIMH also actively supports partnerships, policies and best practices through a range of formats and venues. Staff have led efforts in sharing information about how early childhood experiences influence later health, success, and well-being. In 2014, WI-AIMH Executive Director, Lana Nenide, provided testimony to the State of Wisconsin Legislature Steering Committee for the Symposia Series Supporting Early Brain Development. Strategies such as continuity of care and mental health consultation was shared with the Symposia participants.

WI-AIMH led efforts in establishing an infant toddler policy workgroup. With technical assistance from ZERO TO THREE: the National Center for Infants, Toddlers and Their Families, WI-AIMH staff

facilitated a cross discipline workgroup is developing policy recommendations and priorities for Wisconsin. Priorities included increasing access to mental health consultants, expanding home visiting, establishing infant/toddler specialists and using Medicaid to fund infant and early childhood mental health consultation.

WI-AIMH is the voice for babies in Wisconsin and staff participate in a variety of state advisory and policy meetings promoting the integration of infant mental health practices within service delivery.

Conclusion

The research is clear, early relationships matter. Social and emotional competence sets the stage and is the foundation for all later development including cognitive, language, and physical growth. With 700 new neural connections made *every second* in the first three years of life, we cannot afford to wait. WI-AIMH will continue to increase awareness, develop professional capacities and foster partnerships, policies and best practices supporting healthy social and emotional development.

Additional Information:

Wisconsin Alliance for Infant Mental Health: www.wiaimh.org

ZERO TO THREE: the National Center for Infants, Toddlers and Their Families: www.zerotothree.org

National Child Traumatic Stress Network: <u>www.nctsn.org</u>

Center on the Social and Emotional Foundation of Early Learning: http://csefel.vanderbilt.edu/



THE MADISON MODEL

THE FOUNDATIONAL YEARS

THE MADISON MODEL

THE FOUNDATIONAL YEARS: KEEPING THE FOCUS OF TREATMENT IN THE COMMUNITY

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THE MADISON MODEL

THE FOUNDATIONAL YEARS: KEEPING THE FOCUS OF TREATMENT IN THE COMMUNITY

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LeCount, David. (1998) *The City of Madison, USA: The Madison Model, Keeping the Focus of Treatment in the Community.* In David Goldberg & Graham Thornicroft (Editors), *Mental Health in Our Future Cities* (page 147-171). East Sussex, United Kingdom: Psychology Press Ltd, Publishers.

Introduction			
<u>IMAGE #1.1</u>			

Skyline view of downtown Madison's isthmus

The July 1996 issue of *Money* magazine ranked Madison, Wisconsin as the best place to live in America, based on its vibrant economy (1.7% unemployment rate and plentiful jobs), excellent health care and educational systems, and low crime rate. In addition to being a great place to live and work, it is also a community with a rich tradition of working together in solving problems. Madison achieved the highest ranking in health care, which is largely provided through four primary managed care companies called Health Maintenance Organizations (HMOs). Located in south-central Wisconsin, Madison is home of the state capitol, and makes up approximately half of the 488,000 (2010 census data) residents of Dane County. As home to the University of Wisconsin-Madison and many governmental agencies, there exists an almost recession proof economy in Madison. Surrounded by plentiful lakes, dairy farms, and biking trails, the half-mile wide isthmus with the state capitol at the center is where the core public mental health programs exist, in proximity to many of the consumers of mental health services. It is against this backdrop that the adult mental health system (The Madison Model) evolved since its inception in the mid-1970s.

Another advantage of living in Madison has been the leadership of excellent clinical psychopharmacologic, community oriented psychiatrists in generalizing research into practical application within the context of community-based treatment. While there has been resistance from the psychiatric profession in general to deinstitutionalizing patients because of risks and liability issues and an absence of responsible, community-based alternatives, in the community of Madison, the concept of "the dignity of risk" has taken on great significance in the total evolution of the system. Psychiatrists have assumed primary leadership in the development and

sanctioning of the Dane County (Madison) system. The senior psychiatrists have taught the psychiatric residents concepts of community psychiatry and interdisciplinary teamwork to maximize community integration. The Mental Health Center of Dane County (MHCDC)¹ has provided in vivo training in their core psychiatric programs for these residents. Many of these psychiatrists have continued to work in this model following their training, as well as carrying on the tradition in other parts of the country and world. Community oriented psychiatrists have provided significant and practical applications, as well as pioneering approaches reflected throughout this narrative. Indeed, many of the primary philosophical principles that are a hallmark of this system have been developed and promoted by the seminal psychiatrists. As a result of the above, the dignity of responsible risk has taken on significant meaning in the "Madison Model." Community oriented psychiatry has carried forth and fostered this tradition into its present day form.

Since its inception in 1974, the adult mental health system, administered by Dane County (Madison Model), has been widely recognized as a model for replication elsewhere. Since 1974, it has evolved to its current form, a comprehensive and integrated continuum of managed care for persons who have a serious and persistent mental illness. The Program of Assertive Community Treatment (PACT), begun in 1972, was a precursor to the core continuous treatment teams currently administered through the county's system of care. The PACT program demonstrated the efficacy of community-based treatment by 1976, and many of its proven treatment strategies have been generalized to the larger system in its present form. Since 1980, most of the Community Support Programs (CSPs) are now provided through the Mental Health Center of Dane County's four programs serving 350 consumers. As a state administered outpatient program, PACT continues to be a part of the Madison Model, representing one of the forty programs currently under contract with the Dane County Department of Human Services. It provides services to 133 of the 1,537 consumers who qualify as having the most serious and persistent mental illnesses. Additionally, many single service programs continue to operate, but all are held together through contracted relationships, central entry points, and fixed case management responsibilities. Today, the entire system of care is referenced as an integrated community support system.

II. PIONEERING RESEARCH AND CSP LEARNING CENTER

The PACT program, as a pioneer and prototype model, is well known for demonstrating that in utilizing a continuous treatment team, most consumers can be stabilized and treated in the community, hence minimizing the need for periodic and repeated hospitalizations. This program's control group, which receives primary treatment from the Dane County system, currently more closely approximates the results of the PACT program, particularly in regard to decreased levels of psychiatric hospitalizations. Many research studies have been conducted on various aspects of the Dane County system, and have resulted in the publication of numerous professional articles and book contributions.

IMAGE #1.2

Originally known as The Mental Health Center of Dane County (MHCDC), this multi-program agency has since changed its name to Journey Mental Health Center (JMHC). The agency will be referred to by its original name throughout this prose.



Kennedy Building – The Mental Health Center of Dane County, Inc.
On the West Side of the Downtown Madison Isthmus

For many years, Dane County's system of care through the Mental Health Center of Dane County was designated by the National Institute of Mental Health (NIMH) as a "National Community Support Training Resource Center." Mental health professionals throughout the world have received training from the many programs in Madison. Mental health professionals from Dane County have also consulted nationally and internationally, and have received recognition for their innovative work. Thompson et. al. have concluded: "The success of the experimental clinical trials and imprimatur of NIMH have lead many program planners to see the Madison Model of community care as a basic structure on which to build their own public mental health care systems. In addition, the experience of Dane County frequently serves as a reference point for measuring the achievements of other systems of care" (Thompson, et. al., 1990, p. 625).

In 1984, the Dane County system received the National Association of Counties "County Achievement Award for Human Resources: Special Population Community Mental Health Services." In 1986, the Public Citizen Health Research Group (Washington D.C.) ranked the state of Wisconsin number one in the country for its provision of services to people who are seriously mentally ill. This ranking was primarily achieved because of the services provided in Dane County. E. Fuller Torrey, M.D. and Sidney M. Wolfe, M.D. stated in *Care of the Seriously Mentally Ill* – A Rating of State Programs: "Wisconsin has achieved a national reputation for excellent services for the seriously mentally ill primarily on the basis of the programs in a single county (Dane County) (1986, p. 48)." Since that time, the Dane County adult mental health system has continued to make improvements through the provision of more comprehensive and better community-integrated services.

Ironically, even though the PACT prototype and the Madison Model have been widely studied, evaluated, and disseminated, there are many aspects of their programmatic success that remain unique and are not well publicized or understood. Since its inception twenty-three years ago, the Madison Model has maintained a focus on community treatment. The following highlights reflect how this emphasis has been maintained.

CENTRALIZED MANAGEMENT AND OVERSIGHT

One of the most distinguishing features in the Dane County system is that the primary oversight of the entire public system is fixed in one central agency, which significantly enhances the ability to provide a well-coordinated system of care. The Wisconsin State Statute dealing with disabilities, Chapter 51, was revised in the early 1970s, to reflect the change from hospital to community as the focal point of treatment. This comprehensive legislation mandated that counties be responsible for the planning, development, budgeting, delivery, monitoring, and evaluation of mental health services relegated to the public sector. Chapter 51 included a patient bill of rights section, specified that treatment occur in the least restrictive environment, and provided for a dangerousness standard and due process for involuntary treatment. All court ordered services then became a mandated responsibility for the counties to implement and it required counties to pay for all services, including inpatient treatment. Chapter 51 further specified that all services be authorized and statistically reported, tracked, and evaluated. Finally, it changed the status of state hospitals (which currently number two) from long-term treatment settings, to acute treatment, meaning other inpatient alternatives needed to be used if stabilizations efforts were not successful over time.

Wisconsin's innovative legislation proved to be a cornerstone in the evolution of the mental health system that is located in Madison. It was necessitated by the deinstitutionalization movement that preceded the development of responsible, community-based treatment resources. Up until this time, the hospital was the focal point of treatment – which resulted in a high rate of recidivism. Counties quickly established Community Services Boards and set about the mission of developing community-based mental health services without any master plan to follow. Although demands were real, solutions were relatively unknown. What has been true throughout this grand community experiment is that service innovations are needed to make community living more humane for people caught in this journey. The bifurcated system that existed in the beginning continues today: the private sector provides traditional mental health services (such as psychotropic drugs and psychotherapy) for people with insurance and/or the ability to pay, while the public sector provides the more comprehensive services to those with the highest needs and those with the least ability to pay. The first responsibility of the community boards was to define to whom they were to provide services, as the mandate broadly encompassed the mental health needs of all indigent people, and funding was sum uncertain.

TARGET POPULATION

Within a period of six years (1974-1980), it became clear that the public sector's primary responsibility was to those most in need, requiring a system of care not previously available. The Alliance for the Mentally III of Dane County (AMI), which originated in Madison in 1977, provided an additional impetus in clarifying who should

receive services. Today, over 1,500 persons with the most severe schizophrenic and affective disorders receive the preponderance of the services, and another approximately 3,000 people receive more limited interventions. Many other people with dual mental health and substance abuse disorders and multiple disabilities are also the public sector's responsibility. Physical disabilities related to psychotropic medications, lifestyle, symptoms, and infirmities of aging are rapidly increasing, as the population grows older. Treatment of many disabilities are incorporated into the existing system directly, or as in the case of physical care, coordinated through the primary care physician in the private sector.

SYSTEM MANAGEMENT

While the state legislation clearly fixes the responsibility with the counties to provide comprehensive services, each county has the option to either provide directly, or contract out for the provision of services. Dane County has always elected to contract for services based on the cost savings this represents and the availability of well qualified existing private, nonprofit agencies such as the Mental Health Center of Dane County. Today, there are seventeen different agencies and forty programs providing services through this contractual arrangement creating a public-private partnership. Through these contracted relationships, central entry points are established; duties and responsibilities are defined; services then become authorized, monitored, and reported (Management Information System); and performance indicators are specified – all in an effort to meet the needs of the target population. System management functions are implemented in the following ways:

The provider system has decentralized entry points to services, basing service delivery on the presenting need. Decentralization is possible because each provider agency has identified with the entire system and operates in agreement with the basic tenets and service design of the entire system. The Emergency Services Unit (ESU) is the gatekeeper and authorization agent for all psychiatric inpatient admissions paid for by the County. Supervised living arrangements, case management services, and Community Support Program (CSP) services, are all arranged through a separate Centralized Referral Exchange program. The only exceptions pertain to the PACT program, which does its own intakes following their prescribed research protocol, and ESU, which determines who is placed in their Crisis Home program. Work-related services are authorized at the county level in most instances. All other services are authorized by contracts based on statistical reporting to the County. In other words, many programs do their own intakes and determine whom to serve based on specified eligibility criteria written into their contract.

Within each program, case managers are assigned to each consumer, with their duties and responsibilities clearly defined. If a particular consumer is involved in more than one program, the internal case manager spending the most time with that consumer is designated the system case manager, and acts as the primary coordinator of total programming for that consumer.

- At the county level, there is a central tracking system that reviews the case management assignments to eliminate any duplication, as well as assure that each consumer has a system case manager. Services that are mandated or court ordered are also tracked at the county level to ensure that required services are provided in a timely manner.
- Special features in the contract define service delivery expectations and how programs work together as a coordinated system of care.
- The Emergency Services Unit acts as gatekeeper to inpatient mental health services and also monitors all civil commitments and settlement agreements (court-ordered services) to assure treatment compliance.
- Corporation Counsel employed at the county level acts on behalf of the County in all
 involuntary court proceedings (civil commitment, incompetency/guardianship, and
 protective services/placements). The County's Adult Protective Services Unit is also
 involved as petitioner in the protective services process and monitors services in
 keeping with court orders.
- All contracted providers are required to report hours/days or units of services according to standard program categories (SPCs). Services must be reported that originate from the following programs:
 - Inpatient
 - Day treatment
 - Case management
 - Community support program (CSP) services
 - Community-based treatment facilities (group homes)
 - Adult family homes (foster care)
 - Crisis intervention
 - Counseling/therapeutic resources (psychotherapy/psychotropic medications)
 - Intake & assessment
 - Supported employment
 - Outreach
- Performance indicators are written into the contracts, many of which are related to consumer satisfaction with the services received. The overall perspective in tracking outcome measurements from the entire system is to ensure that the following are met:
 - Those consumers most in need are given priority for comprehensiveness of services
 - At least eighty percent of funding is maintained in community-based services
 - Per-person cost is monitored
 - Average length of inpatient hospital stay is maintained or reduced

- Ninety-five percent of consumers reside in the community, rather than in institutions
- Persons in supervised living arrangements are monitored to keep these placements transitional, with the goal of achieving more independent living
- Consumers with paid work, including hourly wages & number of hours worked, are monitored
- Intra-system and inter-system meetings are scheduled on a regular basis along with ongoing consumer system team meetings: to clarify roles, discuss client-specific issues, and identify system changes. This particularly happens around cases where there are issues that interface between systems, such as with the criminal justice system, benefits procurement system, housing network, and emergency response systems.

B.COST AND CLINICAL EFFICACY

The Madison Model has from its inception had to cope with limited funding and risk liability by developing a system of care that is both cost effective and clinically effective. A conscious guiding principle has been to concurrently emphasize therapeutic interventions that are effective, requiring the system to work in tandem with all related networks to maximize its effectiveness.

Every aspect of the system has been created and designed with the concept of cost effectiveness and clinical soundness in mind. As stated in an article reviewing the history of the Madison Model: "The ultimate stated goal of the system is to provide the lease expensive mix of services necessary to enable each patient to live in the community, minimizing patients' relapses while maximizing their independence and quality of life" (Thompson, et. al., 1990, p. 630).

Most services were planned and developed with the assumption that community-based alternatives would reduce the need for high-cost inpatient services. In reality, it took until 1981 before this goal was achieved. At that point, monies saved were realigned into community services. However, even with maintaining the average length of stay at fifteen days over the past ten years, the cost of inpatient care at the state hospital has increased dramatically, from a rate of \$78.00 per day in 1978, to \$551.00 per day in the late 1990s. The present annual cost of care for one patient at the Mendota Mental Health Institute (the state hospital located on the north side of Madison), comes to \$201,115.00. With a current budget of \$13,244,100 to serve 1,537 people who have serious and persistent mental illnesses, the average cost per person is approximately \$7,324. The chart below shows that over one year's time, twenty-seven people can be served in the community for the same cost as one person on an inpatient basis. While over 4,000 people receive some level of service in the adult mental health system, approximately eighty-five percent of the funding goes for services to people most in need and most severely impaired.

DIAGRAM #1.1

COST DIFFERENTIAL: INPATIENT VS. COMMUNITY (MID-1990S DATA)

Contracting for services was a conscious decision made early on because of the numerous and well qualified private nonprofit human service agencies already available in the Madison community. Studies indicated that in many instances, the County can provide services at a reduced cost by outsourcing. The contracted system provides a wide range of cost-effective services throughout this stratified continuum in the following ways:

- The high cost institutional centers have been minimized. Core psychiatric services are provided through the Mental Health Center of Dane County, and many other case management, work services, and programs that emphasized psychosocial and functional needs are being provided at a lower cost by other providers.
- As stated above, most of the community-based programs have been added over the years to reduce hospital utilization, not only from a cost and treatment standpoint, but also because of consumer preference and to meet court-ordered requirements mandating the least restrictive treatment environment. The development of the Community Support Programs and supervised living arrangements has significantly contributed towards this end. For example, for one program alone, Crisis Homes, the coordinator estimated that 483 inpatient days had been avoided during 1996, achieving a net cost savings of \$258,567 for the system.
- Assistance (a federal/state insurance program), cost-effective solutions were developed to provide more psychotropic drug services for persons unable to access the private sector. Over 400 additional persons gained access to psychotropic drugs with the creation of a separate medications unit, called the Medical Services Unit, at the Mental

Health Center, where nurses with R.N. degrees and psychiatrists efficiently serve individuals requiring psychotropic medications. More recently, an increase in the number of people receiving psychotropic medications has been achieved with psychiatrists consulting at family practice clinics (primary health care centers staffed by general practitioners serving low-income persons) and psychiatric residents providing a medications clinic at a homeless shelter.

DIAGRAM #1.2

ROLE DELINEATION

Role delineation is well defined in the system so cost effectiveness can be achieved with greater treatment efficiencies. Correspondingly, the concept of role blurring (generalists) has been incorporated into the subculture of the human services delivery system and related networks. While case management functions and psychosocial interventions within mental health cross many disciplines, there is a great amount of respect for the particular expertise that each profession brings to the treatment process. It is understood that specialized functions such as making diagnoses, performing psychological testing, prescribing psychotropic medications, ruling out non-psychiatric medical issues, performing mental status exams, and assessing work/living/general functioning all require specialized training, expertise, licensure, and certification. Whereas helping consumers learn new coping mechanisms and problem solving skills is not only relegated to psychotherapist, but is a part of the everyday communication process with consumers across all disciplines. Role delineation occurs in many ways. The work time of psychiatric personnel is always at a premium, and so it is used primarily in a medically necessary and cost-effective manner. Psychiatrists, along with psychiatric nurses, focus on the psychotropic drug needs of consumers. Psychiatrists complete psychiatric workups and make referrals to other medical specialties, as needed. In addition to being consultants to treatment teams, psychiatrists also endorse and respect the roles of all other involved professionals. In the Emergency Services Unit, psychiatric social workers, nurses, and other personnel complete crisis assessments and involve a psychiatrist only, as needed. Vocational rehabilitation counselors may initiate work assessment and placement, with ongoing support being provided by the employer or another staff member. In some programs, occupational therapists take the lead in assessing Activities of Daily Living (ADLs) skills. However, all staff can assist in teaching skills for living successfully in the community. The following table shows the number of staff by discipline per 100,000 population.

TABLE #1.1
STAFF PROFILE

DISCIPLINE	TOTAL	PER
Psychiatrists	10	2.50
Registered Nurses	45	11.25
Social Work &/or Related Master's Degree Staff	70	17.50
Licensed Psychologists	3	0.75
Bachelor's Degree Staff	80	20.00
Non-Degree Clinical Staff (Mental Health Technicians)	30	7.50
TOTAL	228	59.50

Consumer (peer) support is being incorporated into the various facets of our treatment network on a paid and volunteer basis. Consumers are employed in supervised living settings, the Emergency Services Unit, and Community Support Programs. A minimum of seven consumer operated organizations also function independently from the existing contracted system. Other self-help peer support groups are incorporated into existing programs, such as Yahara House. The AMI has numerous ongoing support groups for consumers and affected family members, and also provide educational programs, such as "Journey of Hope." Consumers are involved in planning and hiring processes, and serve on provider boards and other decision making committees. Natural support systems are encouraged and supported throughout the system.

All of these factors provide services to more people at lower cost, fostering both effective treatment in the community, as well as ongoing recovery.

III. MATURE SYSTEM OF CARE

Deinstitutionalization has been largely accomplished after many years, with over ninety-five percent of the consumers now living in the community and receiving some degree of community-based services. Most of the county mental health consumers reside in integrated scattered site apartments while receiving external supports. As a result, they have become more fully integrated into the community. Contrasted with their predecessors, the current generation of mental health consumers have not experienced the great degree of institutionalization and its related problems, such as dependency and missed opportunities.

Maturity of care has also occurred through the budget expenditures and distribution, as it provides a comprehensive continuum of care, exemplified in the below chart (Diagram #1.3). For many years, over eighty percent of the funding has gone for community-based treatment, with less than twenty percent for inpatient psychiatric treatment. This is with the belief that the community is the most therapeutic environment, providing the greatest potential for self-fulfillment. In its present form, this funding distribution represents a balanced and stable system of care that is to be maintained. If cost overruns are seen in inpatient accounts, further analyses are made to determine needed corrections, either through system change or programmatic enhancements. Presently, as the system is at capacity, the challenge is in dealing with both extensive waiting lists and increasing inpatient costs.

The maturity of the system is further manifested in the evolution and funding realignments that have occurred since its inception. The primary redistribution initially occurred by decreasing the funding for psychiatric inpatient services and providing more money for community-based services. Contract performance decisions have guided other funding realignments, as well as the inability of certain programs to meet the country's requirements of an integrated system of care. In all instances, these realignments have positively enhanced treatment programs.

A representative example of this was the startup of the Crisis Home and Short-Term Care programs in 1988 by diverting funds from a high cost group home that had become more of a permanent than a transitional setting. The continuum of networks is apparent in its present form. Other aspects of system maturity will be covered later.

DIAGRAM #1.3

FUNDING DISTRIBUTION PROFILE (1997 DATA)

COMMUNITY-BASED SERVICES (84%) VS. INPATIENT SERVICES (16%)

The maturity of the system as it has evolved into its present form represents a mutual programmatic interdependency in order to perpetuate and maintain its balance. If consumers cannot receive more intensive services on a proactive basis in the community because the system is at capacity, they will likely require hospitalizations. Further, if the highly structured supervised living arrangement system is not mobile, or if too many consumers are hospitalized at any given time, they may have to wait longer in an inpatient psychiatric facility for community-based alternatives to be arranged. To date, the system has been able to maintain this delicate balance despite remaining somewhat precarious.

TABLE #1.2

FUNDING DISTRIBUTION PROFILE (1997 DATA)

COMMUNITY-BASED SERVICES (84%) VS. INPATIENT SERVICES (16%)

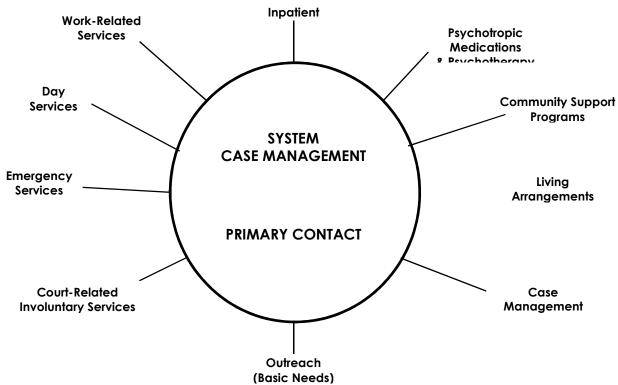
Services	Cost	Percent
Community Support Programs	\$3,570,600	29.96%
Living Arrangements	\$2,884,200	21.78%
Case Management	\$1,481,400	11.19%
Acute/Involuntary Inpatient	\$855,800	6.46%
Acute/Voluntary Inpatient	\$320,200	2.42%
Long-Term Inpatient	\$889,000	6.71%
Crisis Intervention	\$1,073,700	8.11%
Psychotherapy	\$774,800	5.85%
Work-Related Services	\$484,400	3.66%
Day Services	\$462,200	3.49%
Outreach/Miscellaneous	\$393,900	3.97%
Medical Service Unit - Medications	\$53,900	0.41%
TOTAL COST	\$13,244,100	100%

INTEGRATED AND MULTI-TIERED SYSTEM OF CARE

DIAGRAM #1.4

COMMUNITY SUPPORT SYSTEM PROFILE

LEVEL OF SERVICE BASED ON LEVEL OF NEED



As previously indicated, the Dane County system initially began with multiple, single element service component and evolved into an integrated system of care. Loren Mosher and Lorenzo Burti described this model in *Community Mental Health*, *Principles*, *and Practice* (1989). Since that time, a level system has been used to more clearly define how services are matched with needs. This is very much in keeping with principles of managed care. The chart above (Diagram #1.4) illustrates the array of services, which exist on three levels. The below diagram (Diagram #1.5) provides an overview of the entire Dane County Adult Mental Health Services System, as contracted by the Dane County Department of Human Services.

Level I represents core level services. These programs are the most staff intensive, providing assertive outreach and continuous treatment approaches by dealing with consumers at the highest risk for hospitalization. The clinicians working at this level become keenly aware of "soft" signs of deterioration and therefore are more assertive in their treatment stabilization efforts. This level requires all or most services be consolidated within a single treatment team.

DIAGRAM #1.5

ADULT MENTAL HEALTH SERVICES SYSTEM

DANE COUNTY DEPARTMENT OF HUMAN SERVICES

Level II represents some of the single service programs available either at the system's inception (1974) or developed later. This level of programming is available for consumers who are less vulnerable to relapse and able to engage with multiple service providers to have their needs met. They may have a case manager through one program, receive medications through another, and participate in an altogether separate work program.

Level III programming provides for homeless or "unconnected" persons, where goals are to first meet basic needs (food, clothing, & shelter) and then help prepare consumers for treatment. In some instances, they may require involuntary treatment services. Since the core treatment

programs were established (1986), the County has been concentrating more of its contracts with the basic needs network and has established monthly system coordination meetings to focus on getting more of these people into treatment. Staff working at this level are not referred to as "case managers," but are considered the primary contacts, even though they perform similar functions, such as procuring services and building relationships. A recent review of over 100 homeless people followed in this network over a two-year period revealed that over fifty percent were connected with treatment programs during that time. We recognize that with this peripheral network, the process of getting homeless people into treatment can take many years. Connecting timely treatment opportunities to individuals where they reside, on the streets and in the homeless shelters, has been crucial.

Consumers are served at all levels and can rotate among these three tiers, depending upon needs and their ability to be maintained within this system of care. As indicated above, all of the services are coordinated by case managers or staff who act as primary contact points, with centrally defined functions and system oversight. Treatment expectations vary based upon the degree of staff intensity available in each program, which is dependent upon the size of caseloads and amount of time that can be devoted to each consumer. This levels system allows flexibility and change to occur in a more orderly fashion. While the goal of the system is to maintain high need consumers within the most appropriate level of care, it is recognized that consumers are highly mobile, and the system must respond to both positive and negative changes in their condition. For example, consumers remain with Level I programming through a continuous treatment team, even though they have recently been evicted from their apartment and are currently residing in a Level III homeless shelter until another apartment can be obtained. In this system, the homeless shelter is under contract with the County, licensed by the State as a community-based residential treatment facility (group home), and acting as a staff intensive receiving center. Staff at the shelter work with the CSP to reintegrate the consumer back into an independent apartment. The average length of stay at the shelter since its inception in 1988, has been three months.

Particular features of system case management designation are now identified by level of care.

LEVEL I: INTEGRATED, COMPREHENSIVE CORE SERVICES

In addition to the PACT program, there are five CSP teams provided through four programs at the Mental Health Center of Dane County. Day services are modeled after the "Fountain House" program with psychosocial and vocational emphases. The psychiatric inpatient continuum includes Badger Prairie Health Care Center (a county nursing home for long-term inpatient treatment), Mendota Mental Health Institute (a state-operated involuntary acute treatment center), and three community hospitals with psychiatric wards (for voluntary acute treatment). System case management is provided for 650 people at this level.

LEVEL II: MULTIPLE SINGLE SERVICE PROGRAMS

• Twenty-four hour response is available through the Emergency Services Unit. Psychotropic medications are provided by the Medical Services Unit. Four agencies offer short-term solution focused psychotherapy. All forty programs provide case management services, but a Community Intervention Team performs this function exclusively at this level. While supported employment services are available through the CSPs and a day service program, three other programs provide only work-related services. The internal supervised living arrangement system consists

of 201 supervised living arrangements with 102 group home slots in multiple sites, nine crisis home slots, seven short-term care slots, thirty-five adult family home settings, and some individualized living arrangements. Thirty-eight slots are provided in three congregate apartments and three boarding homes, all of which offer minimal staff support. While most of the programs at this level provide only a primary service, there are some exceptions. One example is the Mobile Outreach to Seniors Team (MOST), which offers case management, psychotherapy/psychotropic medications, and consultation services to the county's coalitions for the aging. System case management is provided for 673 people at this level.

LEVEL III: SERVICES INTEGRATING HOMELESS AND "UNCONNECTED" PEOPLE

The main function of this level is outreach. Programs here meet basic needs (food, clothing, & shelter) and attempt to connect people with mental health services through either a relationship approach or an involuntary process. Some of the programs/services here include homeless shelters, a transitional housing program, outreach workers, a medications clinic, and representative payees. Other related networks and agencies are involved, such as law enforcement, emergency response systems, and the Social Security Administration. Primary contact workers serve 214 persons.

IMAGE #1.3

IV.

PRIMARY SERVICE AREAS...

Blacksmith House & Cornerstone

A Community Support Program operated by The Mental Health Center of Dane County, Inc.
Neighborhood program office on Madison's east side

COMMUNITY SUPPORT PROGRAMS SERVICE PROGRESSION

FROM: PACT Demonstrated Research

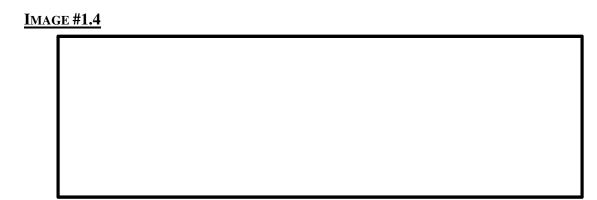
To: System Integration

Although the entire system is viewed as a Community Support Program with many variations on this theme, for the purposes of this section, CSPs will be discussed in relation to the continuous, interdisciplinary treatment teams. Here the majority of their wraparound services are delivered in the community, rather than in program offices.

Since the inception of the County system with the PACT approach arising as the most effective model for persons at highest risk of repeated inpatient treatment, the key variables have been timing, prioritization, funding, and means of implementation. The State worked in conjunction with the Alliance for the Mentally III to realize PACT's implementation on a system-wide basis. The first steps were obtaining a CSP funding initiative in 1980, and obtaining Medical Assistance funding. This latter step set the stage for the promulgation of the 1989 HSS-63 Standards (State administrative rules), which were patterned after the PACT program, enabling more funds for the provision of these essential services. As a result, CSPs have become the predominant emphasis in a budgetary and service delivery sense. Almost one third of the consumers (approximately 483 people) receive services through five programs representing six continuous treatment teams.

There are many features of the Community Support Program. An interdisciplinary team provides assertive and comprehensive services, mostly in the community (in vivo) to address the psychiatric and functional impairments of those most seriously mentally ill. The team treats mental illness symptoms with somatic and behavioral therapy and teaches consumers awareness and self-management of those symptoms. They provide behavioral, supportive, and teaching strategies for dealing with functional deficits, such as limitations in social, vocational, and coping skills, and activities of daily living (ADLs) to enhance successful living in the community. The staff intensity of the CSP allows an increase in service delivery during periods of higher illness acuity. Staff-to-consumer ratios range from 1:8 to 1:13. Outcomes focus on low hospitalization rates (twenty-five percent or less), symptom stabilization, independent living, and paid employment. In addition, one CSP, Community Treatment Alternatives, which only accepts consumers directly from the Dane County jail, has reduced jail recidivism by nearly seventy percent.

Community Support Programs have proven their worth, viability, and cost effectiveness. More CSP slots are needed. Many people continually enter the system and cannot access CSP services, while others are under-served in existing single service programs. Even though PACT has demonstrated the effectiveness of the assertive community treatment approach since 1978, seventy percent of public funding in the broader United States continues to fund inpatient treatment. The National Alliance for the Mentally Ill is currently working to institute the PACT model and its standards throughout the nation.



Parkside Heights Group Home

A group home operated by Lutheran Social Services on Wisconsin & Upper Michigan, Inc.
In Middleton, a suburb adjacent to Madison's west side

A.LIVING ARRANGEMENTS SERVICE PROGRESSION

FROM: Substandard Apartments and Inexpensive Hotels

To: Supported-Living Arrangements

To: Integrated Apartments

Dane County has progresses significantly from the days of discharging people from hospital settings directly to large, congregate hotels and other semi-supervised residences for indigent people, to now providing supportive living environments in the community. Changing times dictated the elimination of most of these outmoded facilities by 1985. The closing of each building was both a crisis and an opportunity to create more individualized and consumer friendly living environments. With the 1982 closing of a large residential care center (166 beds), three additional group homes, an adult foster home, and other less intensive supervised living arrangements were developed through special funding. The goal was to optimize community integration by individualizing and supervising community living. Since then, other living arrangements providing internal staff support have been added.

Today, approximately eighty-eight percent of consumers live in their own apartments, with external staff support. Twelve percent live in a facility having internal staff supervision operated by or contracted with the county. The latter includes thirty-five persons at the Badger Prairie Health Care Center (a county nursing home), 102 in group homes, and forty-eight in adult family homes and other individualized settings. Almost all of these 185 individuals will transition into their own apartments when prepared to live independently.

The evolution of consumer housing from an array of supervised transitional living to a well stratified system of higher to lower structure is shown in the following chart (Table #1.3). In the beginning, it took approximately eighteen months for long-term institutionalized consumers to transition out of high structure living arrangements into more independent living environments. Today, those time frames have been greatly reduced because so many consumers have become better acclimated to the community and require less supervision before taking the next step. At this time, there are no set time periods for consumers to remain in staff supported settings. Currently, group homes with the highest level of staff support are used primarily by consumers coming out of inpatient settings. The supervised living arrangements are mainly

transitional, and are used as a means toward the end goal of consumers living independently with external supports.

TABLE #1.3
SUPERVISED HOUSING PROFILE (1996 DATA)

		Facilities			
		Туре	Quantity	Slots	Served
	highest	Group Homes	9	82.	93
Degree	higher	Receiving Center	1	20	139
Degree		Crisis Homes	9	9	182
of	medium	Short-Term Care Homes	3	3	40
Structure	lower	Adult Family Homes	35	35	48
Structure		Boarding Homes	3	12	16
	lowest	Congregate Anartments	4	40	45
		TOTALS	64	201	563

With the development of a continuum of treatment services, providers and consumers have promoted quality, scattered-site housing instead of the large congregate buildings constructed by the public housing authorities. A "Values Group," whose members included consumers living independently, originated in 1989, to discuss housing factors of importance to them and concluded that integrated, safe, and affordable scattered site housing was their number one priority. Federal Housing and Urban Development (HUD) and county funding, combined with existing staff support (case management services), furthered the availability of supervised and quality independent apartment living arrangements since that time. The timing of our improvements coincided with the change in HUD emphasis from solely constructing living quarters to the inclusion of services to assist in more successful independent living. A private nonprofit agency, Housing Initiatives, was incorporated to disseminate rent subsidies (whereby the consumer pays thirty percent of his/her income for rent), enabling fifty-five persons to reside in higher quality apartments integrated throughout the community. Other housing initiatives have been completed, and additional plans are in the offing.

A recent development is the incorporation into the system of a "Housing Resource Specialist" within the central entry point to track the availability of affordable housing that best meets consumer preferences. Both consumers and providers are kept informed of the available housing stock. In this manner, community integration will further evolve, with the ultimate goal being home ownership.

B.CASE MANAGEMENT SERVICE PROGRESSION

FROM: Single Designation within a Program

To: System-Wide Designation Across Multiple Programs

Case management is the glue that holds the system together. In its purest form, case management functions encompass everything from assessment, treatment of symptoms, rehabilitation planning, interventions, and ongoing evaluation, to coordination and advocacy services for linkage and referrals. As staff-to-consumer rations increase, the expectations become less pronounced. Levels I and II adhere to the purest form of case management. However, in Level III, the primary contact staff provide outreach services to meet basic needs and work over time to connect consumers with treatment. Case managers do not necessarily provide all the services, but must see that all aspects of the treatment/rehabilitation programs are implemented within their program and across all other involved programs.

C.EMERGENCY SERVICES SERVICE PROGRESSION

FROM: Crisis Intervention

To: System-Wide Functions Emphasizing Community-Based Treatment

The nerve center of the adult mental health system is the Emergency Services Unit (ESU), which started in 1968 in response to dictates from the courts. ESU's functions have expanded since then, especially in response to system demands. This energized unit works like a beehive, exemplifying the essence of creative problem solving at all levels. Staff at ESU interact with law enforcement personnel and an endless number of other community resources. They work particularly hard to strengthen natural supports of the consumers, sometimes serve to fill gaps in the system, and although they can provide mobile services, generally respond to consumers over the phone or as walk-ins. ESU is efficient and effective, with its focus always on the community as the primary treatment environment. Essential to maintaining its community emphasis during crisis triage dispositions is its operation as an independent unit apart from a hospital setting.

ESU was initially designated as the "gatekeeper" or entity for authorizing inpatient hospital admissions. It was not until 1980 that its functions were broadened to include ongoing monitoring, facilitating, and implementing aftercare placements for all authorized admissions. This approach has more effectively minimized the use of hospitalization.

Acting as the clearinghouse for inpatient admissions also affords ESU the opportunity to explore outpatient alternatives. All of the services developed over the years in lieu of inpatient treatment can now be fully utilized. According to ESU's 1996 outcome data, sixty-seven percept of the 1,413 requests for hospitalization were diverted to community treatment alternatives, many of which included follow-up of the consumer in the Crisis Unit or placement in a Crisis Home. True creativity emerges when ESU staff respond to a person experiencing

stress and anxiety by capturing what the consumers want and need to help them cope. Sometimes this means just having the consumer be with a friend or family member, or other natural supports. This approach frees up money for "capture the moment" type of plans, such as providing a cup of coffee with a peer at a fast food restaurant.

Staff at ESU have a unique relationship with law enforcement, one that involves mutual training. A clear definition of roles exists in that law enforcement defines alleged dangerousness and ESU staff determine mental status, while both work toward an end disposition. This level of triage produces the most clinically and cost-effective disposition and conforms to the statutory requirements of least-restrictive alternatives. Policy at the Madison Police Department is that all person's potentially needing psychiatric hospitalization, or who appear to be in a mental health crisis, be taken to the ESU for assessment and assistance in disposition.

ESU monitors civil commitments and settlement agreements to ensure that treatment requirements are met. As a part of this process, they also write a report to the court before the expiration of the commitment specifying their recommendations regarding extension or lapsing of the commitment. Crisis alerts can be established with ESU largely through the provider system when it is known a consumer is decompensating and may need a higher level response. Staff at ESU then work with the referring source to see that all voluntary, outpatient alternatives are applied.

ESU provides an all-important 24-hour phone service for all eligible Dane County citizens needing a mental health response or experiencing a mental health crisis. ESU also provides an onsite staff linkage to the homeless shelters, thereby facilitating entry into the mental health system.

Crisis Homes, which are certified adult family home sponsors, are under the direction of ESU and are frequently used in lieu of hospitalization altogether or to shorten the length of inpatient stay. Of all Crisis Home placements, approximately forty percent are in lieu of a hospital admission, forty percent facilitate an earlier discharge from the hospital, and twenty percent represent a pre-crisis intervention or some sort of housing issue. Recent feedback from consumer participation in Crisis Homes shows 100 percent satisfaction with the home like atmosphere of Crisis Homes. Consumers identified two features of this alternative that helped them: "time out from a stressful situation" and "being treated like a normal person." Present day consumers who have not experienced years of institutionalization do not see the psychiatric hospital as the only safe and secure setting for them when their symptoms become acute. Rather, they welcome the Crisis Home (living temporarily with a typical family unit), along with ESU backup, as an alternative to hospitalization.

As ESU program used by the entire community is the "Survivors of Suicide" (SOS) support group for the significant others affected by the suicide or sudden death of a loved one. The support of peers and ESU staff helps to enhance coping after a tragic death and personal loss.

Finally, because the system is at capacity, many times the only way a person in urgent need of psychotropic medications can be served is through ESU. In addition to backing up Mental Health Center programs after hours, this is another way Emergency Services back up the entire system.

INPATIENT CONTINUUM DIAGRAM #1.6 PSYCHIATRIC INPATIENT CONTINUUM Many levels of symptom acuity are successfully and responsibly managed in the community. However, authorization for inpatient hospital admission is granted when ESU staff have determined that the level of acuity requires a hospital setting and the presenting disorder can be appropriately treated therein. Two standards are followed: Inpatient treatment is used only when it is effective for the presenting problem; and

All other outpatient treatments have been ruled out

Usually, this means inpatient placement primarily for stabilization of acute symptoms and for special medication titrating. An inpatient exceeding the average length of stay signals a special placement problem, which requires a review at all levels to ensure that either inpatient treatment is still warranted, or all attempts to procure an alternative are being fully explored. Given all inpatient beds available in this community, it is estimated that 24 beds per 100,000 population are used exclusively by Dane County residents. This includes forensics, but not children.

TABLE #1.4
PSYCHIATRIC INPATIENT CONTINUUM (1996 DATA)

State Hospital – acute, involuntary	TOTAL
Admissions	117
Davs	1.597
Average Davs/Person	14
Community Hospitals – acute, voluntary	TOTAL
Admissions	69
Davs	323
Average Davs/Person	5
Badger Prairie (county) – involuntary	TOTAL
Average Davs/Person	365
Crisis Stabilization Homes – voluntary	TOTAL
Admissions	182
Days	542
Average Days/Person	3

The stabilization of inpatient utilization is another measure of the system's maturity. Inpatient treatments range from short-term voluntary hospitalization in community hospitals (average stay is five days), to longer-term involuntary hospitalizations at the state hospital (average stay of fifteen days per episode over the last ten years, from 1985 to 1996) to long-term placements at the Badger Prairie Health Care Center (average stay is one year). Today, thirty-five consumers reside at the locked ward at the Badger Prairie Health Care Center (BPHCC) under a court-ordered, protective placement finding. Approximately one half of these inpatients will be discharged to the community during the course of a year, with the goals of all eventually returning to the community. Many participate in daytime programs in the community to keep them identified with the settings where they will soon be living. The court-ordered psychiatric

^{*} This data excludes people who have the ability to pay, and are authorized for voluntary community hospital inpatient treatment by ESU.

unit at BPHCC first opened in August 1978. For its first six years (1978-1984), the average length of stay at BPHCC was three years. Over the next six years (1984-1989), it declined to two years. During the last six years (1990-1996), the average length of stay has been only one year. This too demonstrates the natural progression occurring with the advent of more community support and better psychotropic drugs, particularly Clozaril.

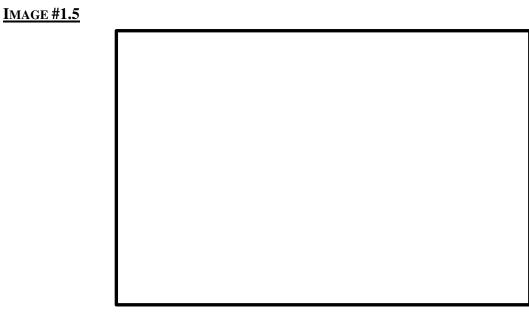
DIAGRAM #1.7

ACUTE INVOLUNTARY ADMISSIONS AND AVERAGE LENGTH OF STAY INPATIENT STATE HOSPITAL (1981-1996 DATA)

DIAGRAM #1.8

ADULT INPATIENT DAYS
INPATIENT STATE HOSPITAL (1977-2002 DATA)

The preceding charts (Diagrams #1.7 and #1.8) depict involuntary inpatient utilization at the state hospital, a key barometer in measuring the effectiveness of community-based treatment. By all measurements, forced inpatient utilization has remained relatively constant for many years in terms of average lengths of stay and number of days, even though the number of admissions has increased. This was accomplished by designating responsibilities in existing programs and adding more alternative community programs, all of which provided for additional responsible and effective community-based alternatives. This stability has been achieved even though funding increases have not been commensurate with higher service demands.



Mendota Mental Health Institute
Adjacent to Lake Mendota on the northeast side of Madison

Most involuntary inpatient admissions are for consumers who are not connected to the treatment system for a variety of reasons. A five-year review of admissions revealed over seventy percent of the admissions to the state hospital (Mendota Mental Health Institute) were first-time admissions for people who had few or no service connections with the contracted system. The implication here is that a more mature system of care allows for proactivity with service connected consumers and hence minimize involuntary hospitalizations or provides brief voluntary hospitalizations in community hospitals. However, there will always be persons new to the system for whom an emergency response is required – a source of unpredictability.

D.PSYCHOTHERAPY AND PSYCHOTROPIC MEDICATIONS SERVICE PROGRESSION

FROM: Long-Term Psychotherapy

To: Short-Term, Solution-Focused Therapy and Group Approaches

In thinking about my experiences with psychotherapy, these are some thoughts that come to mind:

It's not just what you say;

It's how you say it,

It's not just how you feel;

It's what you may not be feeling,

It's not just that I don't understand what's wrong in my life;

It's developing insight and a course of corrective action,

It's not just a feeling of being isolated and alone;

It's knowing that somebody else cares,

It's not just experiencing active acute symptoms;

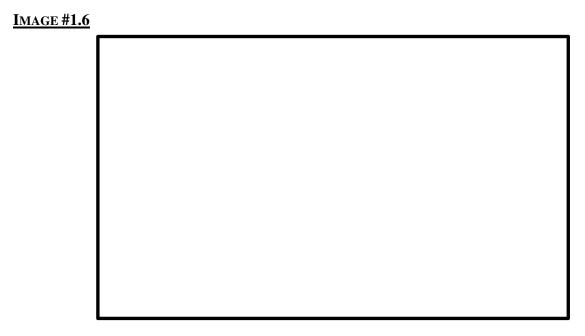
It's feeling some relief they are becoming more subdued.

Talk therapy and psychotropic medications, traditionally a part of the private practice community, have sometimes been difficult to obtain through the public sector. Recognizing this need and realizing the system was falling further behind in meeting psychotherapy and psychotropic needs, cost-effective alternatives were developed in order to serve more people.

Long-term psychotherapy has almost been eliminated within the Madison Model in favor of reaching more people through short-term, solution focused therapy. We have maximized the use of somatic treatments by establishing a separate Medical Services Unit (a nurse-psychiatrist medication clinic), by providing psychiatric consultation to primary health care clinics enabling indigent persons to responsibly receive psychotropic medications, and establishing a medication clinic in a homeless shelter. Multiple agencies are working cooperatively to provide group therapy – a key component in this effort. Therapy groups exist to deal with such varied issues as depression, parenting, divorce, stress, learning assertiveness, surviving sexual abuse, and support for living in the neighborhoods where participants reside. A total of 547 people received these services in 1996, with a high degree of satisfaction reported. These are all examples of creative solutions recently developed.

Specialized, culturally competent psychotherapy programs are provided to persons in the Dane County jail system and to Southeast Asian persons (who primarily have a diagnosis of PTSD) in close proximity to their residences. Programming for both populations is successful because staff related directly to where the person is at (contextual relevance) and because staff are culturally diverse and include indigenous workers. The jail mental health team also demonstrated excellent outcomes last year. Ninety-six percent of 400 people (382) assessed for emergency detention were successfully treated and maintained in the jail, rather than

hospitalized. Sixty-three percent of fifty-two people (thirty-three), who had a serious psychiatric disorder and were not in treatment, were able to access community-based treatment upon release.



Yahara House

A day service program operated by The Mental Health Center of Dane County Inc. Overlooking Lake Mendota, on the east side of Madison's downtown isthmus

E.DAY SERVICES

SERVICE PROGRESSION

FROM: Traditional Day Treatment Psychotherapy Emphasis

To: Supported Employment and Full-Time Independent Employment Focus

Yahara House is the primary day program providing Level I services to over 200 people during the course of the year. While not offering the level of staff intensity and outreach assertiveness available in a CSP, Yahara House is proactive in many instances and also utilizes peer supports. It is patterned after the "Fountain House" model, and offers user-friendly and supportive services to all members who come to the House 365 days of the year. Yahara House is located in a renovated historic building near Lake Mendota. The personal charm and décor of the facility and its location enhance its people supportive milieu. It offers members a variety of groups in which to participate. Transitional employment programs provide paid work for forty percent, or eighty-three members. There is medication dispensing and "med groups" for many members. All members receive case management services. Meals are provided on-site in the Café Yahara, located on the third floor. A retail store called "Hidden Treasures" provides work activity for members at another site, and benefits the community at large. The program also offers quality congregate living through its Stein and Perry Street apartment complexes (which are federal HUD-funded facilities). Staff and peer support are hallmarks of this program. Many different work groups and several consumer self-help groups (Recovery, Inc., Alcoholics Anonymous, and Narcotics Anonymous) offer ongoing opportunities for self-improvement. It's a delight to visit and enjoy a milieu that truly exudes empowerment.

F.WORK SERVICES

SERVICE PROGRESSION

FROM: Sheltered Workshops in Segregated Sites

To: Supported Employment in Work Sites Integrated into the Community

Much of people's identify and self-fulfillment derive from satisfying work activity. It is little wonder that gainful work has become an important treatment outcome for mental health consumers. Frequent discussions with consumers about work and the inherent disincentives in the system have led me to the following conclusion:

"I value my life, my worth, my dignity; can a system be established that will make the risk of work profitable on a personal and financial level?"

Some good things have happened which are promoting gainful employment within the mental health system. Sheltered workshops are "out" and competitive employment in natural community settings is "in." Make-work has been replaced with work based on interests and abilities. Mental health consumers generally do not have to prove themselves based on earlier work performance to move on incrementally to more challenging work. Demeaning assemblyline tasks in segregated sites reinforced daydreaming, which magnified symptoms. These have been replaced with meaningful work in integrated community sites. Also now the employer (rather than a job coach) is often the primary supervisor. Work is being incorporated into existing treatment programs like the CSPs and Yahara House, thus eliminating the need for consumers to have to go through yet another program to enter the work force. Symptom stabilization, the single most significant factor interfering with work for mental health consumers, is better managed through newer psychotropic medications with fewer adverse side effects. When symptoms intensify, alternate plans are developed and implemented, as needed. Medical leaves are common in the work force at large, and are also appropriate and responsible courses to follow for consumers, given the cyclical nature of their mental illnesses. Employment occurs in many different natural work settings and mental health providers are hiring mental health consumers for a variety of positions.

With this new generation of consumers who have never experienced the devastating effects of years of institutionalization, their socialization has not been impeded by the dependency inducing hospital environment. With reasonable work incentives and better treatment, they are more ready to embrace the concept of work. With reasonable work incentives and better treatment, they are more ready to embrace the concept of work. Recent innovations reinforce their entry into employment, such as payment for training and higher education, which assist with both developing gainful employment and maintaining ongoing benefits (government checks and health insurance benefits). An attempt at more equitable mental health insurance on the same level with that of physical health insurance was passed by the federal government in the fall of 1996, providing yet another positive step in this direction.

The following statistics (Table #1.5) show the progress made in employing adult mental health consumers: approximately seventeen percent perform some level of significant competitive employment, and a few consumers have left the security of government checks to be on their own. This remains an important evaluation outcome measure. The table below (Table #1.5) illustrates a net gain of sixty-one employees in paid work over the last six years, with an average hourly pay rate of \$5.46, an average yearly income of \$5,580 per person, and an annual average aggregate amount of \$1,225,788 over all six years. It should be noted that in the PACT program, where the age range is eighteen to thirty (consumers with early onset of illness), the

number of consumers in paid employment exceeds fifty percent. With the maturity of the Madison Model, we anticipate an increase in numbers of consumers in gainful employment. For more and more consumers, full-time employment will become the goal.

With continued exposure, consumers achieve increased feelings of fulfillment and self-worth, providers get the satisfying realization of a better treatment outcome, employers obtain good employees, and the community gets productive and contributing members of society. We are committed to keeping this synergistic cycle evolving.

TABLE #1.5
PAID WORK IN COMMUNITY WORK SETTINGS

	1991	1992	1995	1996
Number of Consumers Working	196	200	220	257
Average Hourly Wage	\$4.90	\$5.13	\$5.83	\$5.97
Average Hours Worked/Week (per consumer)	20.00	20.80	18.41	19.60
Average Earnings/Year (per consumer)	\$5,101	\$5,550	\$5,582	\$6,090
Annualized Aggregate Earnings	\$999,821	\$1,110,017	\$1,228,200	\$1,565,116

V. COURT-ORDERED INVOLUNTARY PROCESS

While the great majority of services are provided on a voluntary and mutually agreed upon basis, the involuntary process provides a further element of stability within the community and for the system. Significantly, the involuntary system is one of the most confusing and lease understood aspects of the adult mental health system. Corporation Counsel and court-related experts have been essential to a properly working system. Knowing who to call and under what circumstances are also critical elements. In every community of the state; attorneys, the courts, law enforcement personnel, and mental health professionals have developed their own community practices based on their interpretations of the state standards for involuntary commitment. The Madison community has attempted to uphold the highest criteria of state statutes. Through careful monitoring of court orders for commitment, a high level of credibility has thus been attained.

In terms of dangerousness, highly sensationalized media portrayals have perpetuated the myth that mentally ill persons are more likely to be dangerous to others. In reality, they are much more likely to be dangerous to themselves – either through omission or overt self-destructive acts – or to be victims of crimes. In this community, we clearly understand that untreated or undertreated individuals with documented histories of dangerousness to others can once again pose threats to other people. Therefore, mental health professionals work closely with the law

enforcement and judicial systems to assure that clients and society are better protected when treatment persons with a history of dangerousness – meaning treating clients on an involuntary basis at times. Society's mandate for safety underscores the need for comprehensive community-based treatment with a capability for assertive outreach.

The involuntary processes in Dane County have been well defined and enforced. Corporation Counsel represents the County in civil commitments, incompetency determinations, and protective placement/services findings. The Adult Protective Services Unit at the county level also works with Corporation Counsel, acts as the petitioner for guardianship and protective cases, and completes psychosocial assessments for privately initiated cases. It also monitors placements and services once court orders have been instituted. A Clinical Assessment Unit at the Mental Health Center of Dane County completes the psychosocial reports and makes recommendations that frequently become incorporated into court-ordered services. The primary respondent is the Emergency Services Unit, whose staff work with law enforcement to comply with the Chapter 51 mandate for treatment in the least restrictive setting. Forensic findings are determined through the criminal justice system. In all court-related circumstances, clients have their own attorneys, and due process protections are in place. It is the County's duty to see that all civil court-ordered services are implemented and monitored for compliance with state statutes.

The breakdown of involuntary services for 1996 included a total of 373 persons under involuntary findings, or twenty-four percent of all persons (with a serious and persistent mental illness) receiving services, which included the following:

- 119 under civil commitments
- 75 under settlement agreements
- 158 in protective services/placements
- 21 conditionally released (forensic clients)

In addition to the number of persons under involuntary findings in any given year, there are others who have as a condition of their probation or parole status, the taking of psychotropic medications. For these people, noncompliance can lead to placement in the Dane County Public Protection and Safety Building (jail), where mental health services are provided in an internally secure environment.

VI. IMPROVING CONSUMER QUALITY OF LIFE

Many sections of this chapter have focused on the positive aspects of individuals working together to improve consumer strengths and promote acceptance and community integration. The sections regarding living arrangements and work-related services are especially illustrative. The focus is not just on providing treatment – it's promoting a quality of life. This involves community awareness, acceptance, and raising consumers' standard of living. It's also having fun and recreating. Its feeling inspired. It's everyone working together.

Following more than two decades of treatment services focused on community integration, mental health consumers are feeling more empowered and better able to embrace the concept of recovery. The hope is that with ongoing community exposure and participation of mental health consumers, their recovery process will be enhanced by the community's acceptance. No longer is it true that adult mental health consumers isolated away in state hospitals with no hope for the future can be ignored by the surrounding community. The need to belong, a universal psychological need, can be fulfilled through the community's benevolence in providing employment, safe and affordable housing, and natural support systems; by acting as guardians; and by befriending persons with special needs. These all reduce stigma and isolation. We are working together as a community to make this happen.

Presently, there appears to be a better understanding of a holistic approach which is having a positive impact on personal development and the ongoing self-recovery process. The commitment continues to be toward working together in reinforcing and promoting the personal intrapsychic and interpersonal development of adult mental health consumers. When professionals recognize and support the spiritual – motivational and inspirational – aspects of the consumer's personal development journey, the horizons of the adult mental health consumer expand. The path each person chooses to follow will be enhanced if we can mutually understand and promote the importance of natural supports, self-determination, and individualization. Relationships will be established on the basis of mutual trust and respect. Even though the recognition and treatment of core symptoms are tasks of the mental health professionals, attention to clients' psychosocial functioning involves the entire community. Quality of life involves housing, employment, and recreation as important facilitators of the personal growth process; so too are the community's acceptance of employing consumers and the enhancement of peer support services and networks. In addition, a strong appreciation of holistic self-discovery is essential to each person's self-fulfillment and ultimate life satisfaction. This process will continue to evolve and energize, leading to a new level of personal development and community integration.

VII. CONCLUSION

I close with the critique provided by a mental health client following his reading of this preliminary report. Mr. Edward Erwin has been a long-time member of Yahara House. It is reproduced with his permission.

"Dignity of risk" is held up as a primary option for consumers. More importantly, it is a theme for management in an extremely responsible manner. The sense of values guiding decision making resulted in a system to which many owe much. I have, and continue to be, a part of this wonderful "mortal system." Its touch is something grown into it, and its caring too often taken for granted, even by myself.

I was struck by the sentences...

"All of the services are coordinated by case managers with centrally defined responsibilities (functions). This allows for the flexibility and change in an orderly fashion."

I have felt the truth of this more than I have known it in these many, many years. My own and my peers' internal and external lives fit into the motion of our environment. It is our way of life. And we too often just live through rather than with these policies through levels of response to our own actions and those of others.

It is impossible to sever oneself from a bureaucracy to which one is medically bound. It is also impossible for me to not look upon it as part of my own plans. Having passed through the system so far, I have my own questions as much as the mental health system does. Where to from here? My only comment, based on seeing its evolution, is this: I have confidence."

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Challenges that Remain

The Consumer Experience

- Through language, media portrayals and the inaccurate equating of violence with mental illness
 people with mental illnesses continue to be confronted with stigma that results in discrimination
 that impacts their ability to achieve full integration into society. Use of the term "behavioral
 health" by treatment providers unfortunately seems to take the focus back to blaming the person
 and his/her family about their behavior and ignoring the biological contributions to mental
 disorders.
- The inclusion of consumers and families in policy development and planning is inconsistent; some counties and some state agencies do a good job, others do not. We are seeing efforts at the national level to pushback against consumer/family involvement and return to a more medically directed system.
- Peer run programs/peer delivered services have been popular with consumers but have traditionally been undercapitalized, preventing them from achieving long-term sustainability.
 Mental health administrators continue to view consumer run/peer delivered programs additional services rather than being the core of consumer recovery.
- The criminalization of mental illness continues to make jails and prisons some of the largest mental health facilities in our communities resulting in mass incarceration of persons with these disorders. Individuals with mental illnesses are over represented in the criminal justice system due to insufficient number of evidence based community outreach and treatment programs. Treatment programs in jails and prisons are inadequate, poorly funded and staffed and incarceration often exacerbates mental illness symptoms and results in re-traumatization. Efforts to create alternatives to incarceration and diversion strategies are extremely limited, and only able to positively impact a small percentage of those who need these services.
- Individuals with serious mental illnesses continue to die younger than the general population due to a variety of factors, including high rates of smoking, cardiovascular disease and metabolic syndrome. Some factors, like suicide, are directly related to the mental illness. Some, like metabolic syndrome, may be related to the medications people are taking for their mental illnesses. Others represent a failure of the health care system to treat the medical problems of individuals with mental illnesses in the same manner as they would treat the same conditions in the general population. Improved integration of mental health and medical care is beginning but is not to the scale it needs to be.
- Recovery concepts continue to be spottily understood and implemented. Mental health service
 systems that incorporate hope and recovery as core concepts in all mental health services
 provided tend to be rare and are often dependent on strong individual leadership of program
 directors and managers.
- Unemployment and underemployment among people with severe mental illness continues to be high. While progress has been made in removing barriers to work by preserving needed benefits and developing evidence based effective supported employment programs, it is still very challenging for people to get and keep meaningful, well-paying work.

- Many people with mental illness continue to live in poverty as many have the Supplemental Security Income (SSI) as their only source of income. The SSI payment in 2015 in Wisconsin was a little over \$800/month or about 20% of median income. This rate of poverty contributes to housing instability and homelessness, transportation difficulties and problems in meeting daily needs increasing the level of stress in the lives of people with mental illness.
- Serious mental illness continues to place a significant burden on families. Lack of sufficient treatment and support services often means that families carry the responsibility of providing practical support in housing and income, as well as the responsibility of connecting the family member to services and coordinating the needed services.

Access to Services

- The mental health system has been chronically underfunded on a number of levels:
 - State and federal agencies have not provided adequate support for mental health services from prevention and early intervention to housing and supported employment to evidence-based community based treatment and support programs such as WrapAround services, Assertive Community Treatment and Clubhouse programs.
 - A limited number of mental health services is available over a long period of time.
 However, many services are available on a short term basis or require complex preauthorization processes. This further limits access of people with severe mental illnesses to effective treatment that they may require for a long period of time.
 - While legislation was passed creating parity in commercial health insurance coverage, there is evidence that plans are using prior approval to limit access to these services in a manner that is not consistent with access to other medical services. Appealing denials of care is extremely challenging for individuals who are in treatment.
 - Medicaid reimbursement for many mental health services is inadequate and prior approval processes remain burdensome; as a result many providers are unwilling to accept Medicaid. Medicaid has recently begun to fully fund Comprehensive Community Services, but counties are still responsible for paying the non-federal share of Medicaid for other psychosocial rehabilitative services. This results in inequities of access to these services across the state.
- There is an <u>inadequate workforce</u> for serving individuals with mental illnesses:
 - Large parts of Wisconsin outside the major metropolitan areas have very limited access to psychiatrists, especially those who specialize in working with children and older adults.
 - Certification of peer specialists has been developed in Wisconsin, but CPSs are clustered
 in the major metropolitan areas. There is a need to develop support for CPSs and to
 educate traditional providers about the appropriate roles for peers. Certification is still
 being developed for parent peer specialists.

Service Quality

• Outcome measurement has not been well defined in the mental health area, resulting in the inability to identify and apply quality metrics across systems. As a result it is not possible to compare and communicate the level of quality of care across counties, health systems or provider agencies. We do not know to what degree providers are utilizing evidence-based or best practices.

- Efforts to promote <u>protective factors</u> in younger children--such as mindfulness based stress reduction, social emotional development, resilience--are promising but are in their infancy. Screening for social/emotional disorders in schools and primary care needs to become more prevalent so that disorders can be identified early and addressed. Models for early intervention for first episode psychosis need to be expanded to reduce the impact of these disorders.
- <u>Trauma-informed practices</u> need to be integrated into all mental health and child-serving systems and the use of seclusion and restraints in schools and treatment settings needs to be eliminated. Trauma-informed care practices needs to be incorporated into all work with children and adults to address the impact of trauma.

Members of the ADA 25th Anniversary Celebration Mental Health Work Group 2014-2016

Nancy Abraham, Founding President, AMI Wisconsin

Mike Bachhuber, Executive Director, Independent Living Centers of Wisconsin (ILCW)

Linda Erdmann, Retired Executive Staff Assistant (DHS)

Dianne Greenley, Retired Supervising Attorney, Disability Rights Wisconsin (DRW)

Shel Gross, Director of Public Policy, Mental Health America of Wisconsin. Former Chair of the WCMH.

Chris Hendrickson, former Director of the Bureau of Community Mental Health, Retired Policy Adviser, Division of Mental Health and Substance Abuse Services, WI Department of Health Services

David LeCount, Retired Mental Health Coordinator of Dane County Department of Human Services, Adult Community Services Division. Currently Field Faculty Associate at UW-Madison, School of Social Work.

Maggie Mezera, former Executive Director of Wisconsin Family Ties, Inc.

John Quinlan, Executive Director, "Voices in Support of Community," an oral history/storytelling nonprofit.

Sinikka Santala, former Director of the Bureau of Community Mental Health, retired Administrator of Division of Long Term Care, WI Department of Health Services.

Dan Zimmerman, Contract Administrator, Bureau of Prevention, Treatment and Recovery, Division of Mental Health and Substance Abuse Services, WI Department of Health Services

Logistic and Consulting Support Provided by:

Jean S. Logan, Wisconsin ADA Partnership/Strategic Partners

Dan C. Johnson, Coordinator of Resources for People with Physical Disabilities, Bureau of Aging and Disability Resources, Division of Long-Term Support, WI Department of Health Services

Helmut Knies, Collection Development Coordinator, Wisconsin Historical Society

Jonathan Nelson, Collection Development Archivist, Wisconsin Historical Society